RESPECT AND PROTECT:

The experience of older people and staff in care homes and hospitals

Commissioned by Comic Relief and written by Carol Lupton and Clare Croft-White

The **PANICOA** Report

COMIC RELIEF

COMIC RELIEF'S VISION

A JUST WORLD FREE FROM POVERTY

Comic Relief does three things. It raises much needed cash; it then allocates that cash to projects to transform the lives of some of the poorest and most disadvantaged people in the UK and around the world, and raises awareness of the issues it feels strongly about. Comic Relief has been supporting work to promote the rights and meet the needs of older people since 1990. We were one of the first funders to put work led by older people at the heart of our grant making. Through grant making, awareness raising and education we have aimed to highlight areas that otherwise might remain hidden.

Our thanks go to Carol Lupton, the author of this report who, supported by Clare Croft-White, has done a great job of pulling together the findings from all the separate research studies into this composite final report.

PANICOA

Preventing Abuse and Neglect in Institutional Care of Older Adults

A RESEARCH INITIATIVE TO ENHANCE DIGNITY IN CARE HOMES AND HOSPITALS

DH Department of Health

COMIC RELIEF

FOREWORD

It is nine years since I accompanied our Chief Executive into the office of Stephen Ladyman, the then Minister for Social Care to ask the Department of Health to join us in funding the first ever prevalence study of the abuse and mistreatment of older people living in the community. That first meeting led to a sustained and productive partnership that has combined the resources and expertise of the Department with Comic Relief's ability to raise awareness in the public domain to this challenging issue. The TV drama 'Dad', on BBC1 watched by over five million people brought the mistreatment of older people - often by members of their own family - into people's living rooms for the first time. The Study of the Prevalence of Abuse and Mistreatment of Older People, published in 2007 provided the first ever robust evidence of mistreatment in community settings.

The second phase of the project, started in 2008, included a series of eleven separate but linked studies looking at the experiences of older people in care homes and hospitals and became known as the PANICOA initiative (Prevention of Abuse and Neglect in the Institutional Care of Older Adults). The research set out to improve our understanding of the context, causes and consequences of mistreatment in institutional settings, and to provide the evidence to help develop more effective ways of preventing, identifying and responding to it.

The issues addressed by the PANICOA initiative regrettably still remain relevant today. From 2011 onwards, a series of high-profile media and public reports has exposed the unacceptable treatment of older people and other vulnerable adults in hospitals and residential settings. Whilst the PANICOA research shows that good care was evident in many locations, privacy, courtesy and respect needs to be at the heart of all care, and sadly this was not the case. In summary, the report shows that abuse and neglect are real but preventable - and that training and support for front line staff are essential. By focusing on practical steps for action, we believe the report can make a useful contribution to help prevent the circumstances where abuse, mistreatment and neglect prevail. We hope that together with a range of other current initiatives, the report will be of value to regulators, providers, commissioners and government, amongst others.

Our key motivation for engaging in this work is simply to improve the lives of older people, and especially those who are frail or vulnerable. Most of us have loved a parent or grandparent as they grew older, and the idea of people like them suffering is terrible - Comic Relief has always been about working on behalf of individuals, and every individual story of pain and mistreatment is unthinkable. Older people themselves can play a significant part in bringing about change so long as we enable their voices to be heard. We are especially grateful to the older people and staff who gave their time and shared their experiences throughout the research. It is their views and voices which has shaped this report. We hope it will bring about change - and the sooner the better.

Richard Curtis

Founder and Trustee
Comic Relief

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D. Guidance and Standards underpinning the PANICOA Framework;

E. The PIECE-dem Observational Framework;

F. 'Inside Out of Mind' - a Playlet;

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INTRODUCTION:

THE HISTORY OF PANICOA

In 2005, Comic Relief's Red Nose Day showcased a drama that surpassed expectations in terms of audience numbers. 'Dad' highlighted the hidden issue of elder abuse and was produced in response to Comic Relief's awareness of growing public concern about older people at risk of mistreatment at home. With the support of Action on Elder Abuse, a meeting was subsequently held between the (then) Government's Minister for Care Services, Stephen Ladyman MP, and representatives from the Department of Health and Comic Relief. This meeting paved the way for a longstanding partnership between Comic Relief and the Department that has benefited from the combined resources, expertise and commitment of both parties.

The first outcome from this partnership was the commissioning of a national prevalence study (O'Keeffe et al., 2007) which aimed to increase understanding of the abuse and neglect of older people living in the community, by identifying the risk factors associated with different types of abuse/neglect, and by examining its impact on older people and their families/carers.

At the same time there was increased policy focus on strengthening adult safeguarding procedures not only for those living in the community but also those in the residential care home sector and NHS hospitals. This prompted Comic Relief and the Department to commission further joint research on elder abuse in institutional settings. This new research initiative became known as PANICOA – Preventing Abuse and Neglect in the Institutional Care of Older Adults.

AIMS OF THE PANICOA RESEARCH INITIATIVE:

- to increase understanding of the context, causes and consequences of mistreatment in institutional settings, from the perspectives of all key participants;

- to provide the evidence to help develop more effective ways of preventing, identifying and responding to abusive, neglectful or disrespectful relationships in institutional settings;

- to increase knowledge of the prevalence of the mistreatment of older people in institutional care and of the means by which it can be ascertained in both hospitals and care homes.

Competitive tendering of the new PANICOA initiative began in 2008 and the final research Portfolio comprised three different types of study: preparatory studies to explore issues of definition, measurement and data availability; exploratory research to examine the feasibility of undertaking prevalence surveys in institutional settings; and primary research in care homes and hospitals designed to help identify and prevent factors leading to the mistreatment of both older people and care staff.

The issues addressed by the PANICOA initiative sadly remain relevant today. From 2011 onwards, a series of high-profile media and public reports has exposed the unacceptable treatment of older people and other vulnerable adults in hospitals and residential settings. The second report into the mid-Staffordshire Inquiry in 2013,

for example, was clear that the hospital had failed to meet the challenge of the safe and professional care of older people to the extent that: *'Some of the treatment of elderly patients could properly be characterised as abuse of vulnerable persons'* (Francis Report, 2013: 25).

This Report does not focus on the individual PANICOA studies (summaries of these can be found in Annexe 2), but rather combines their findings to identify common themes and issues. These are drawn together to provide a series of **Narratives**, reflecting the perspectives of residents and patients, care staff, care organisations and the wider 'institutional care community'. The main messages from the Narratives are combined into two **Templates for Good Practice**, designed to reinforce or improve current practice in respect of both the care service and care culture of provider organisations. The Discussion explores the implications of the PANICOA studies in the current policy

context and the Conclusion is followed by recommendations for **Next Steps** to be taken by the different organisations responsible for the care and protection of older people in institutional contexts.

The following Figure provides a 'data flow chart' indicating the different stages involved in organising and 'distilling' the evidence from the PANICOA studies:

USING THE REPORT

Direct links to further information (about concepts, names, initiatives etc) contained in the **Glossary** are provided by the electronic 'red button'. You can then navigate back to where you were by clicking on the Glossary headings. A list of the **References** for texts used in the Report follows the **Conclusion**.

RESEARCH DATA

FRAMEWORK DOMAINS (Section 3) (the elements of the care experience covered by the PANICOA research)	PANNICOA NARRATIVES (Section 5) (the perspectives of those involved in the care relationship)	TEMPLATES FOR GOOD PRACTICE (Section 5) ('checklists' for maintaining or developing safe and respectful practice)	NEXT STEPS (Conclusion) (recommendations for action on the part of key 'stakeholders')
direct care			care providers
safety & security			care commisioners
dignity & respect	patient/residents (relatives & friends) care staff	a respect & protect care service	safeguarding bodies
continuity		a respect & protect care culture	regulators
involvement	care providers		national health & care bodies
communication	care community		the government
relationships			research funders
identity			
culture			

ACKNOWLEDGEMENTS

EXECUTIVE SUMMARY

INTRODUCTION

PANICOA - **P**revention of **A**buse and **N**eglect in the **I**nstitutional **C**are of **O**lder **A**dults - is a joint research initiative between Comic Relief and the Department of Health, launched in 2008 following successful collaboration on an earlier survey of mistreatment of older people living in the community (O'Keeffe, 2007). Eleven studies were commissioned under the Initiative and undertaken between 2009 and 2013.

The aims of the PANICOA Research Initiative were to:

- improve understanding of the context, causes and consequences of mistreatment, of both staff and residents/patients in institutional settings, from the perspectives of all key participants;

- provide the evidence to help develop more effective ways of preventing, identifying and responding to abusive, neglectful or disrespectful relationships in institutional settings;

- contribute to knowledge on the prevalence of the mistreatment of older people in institutional care and the means by which it can be robustly ascertained in both care homes and hospitals.

The definition of 'mistreatment' was intentionally broad, including: physical and mental abuse; neglect or loss of dignity resulting from the actions, or inactions, of care staff; as well as the behaviour of residents/patients and care organisations. The financial abuse of residents/patients was not covered. The PANICOA Initiative was also broad in focus, including: both care homes and hospitals; care staff as well as older people; and the operation of care provider organisations, both internally and in the context of the wider 'institutional care community'.

THE PANICOA EVIDENCE

The PANICOA initiative commissioned a range of different studies to examine the complex issue of mistreatment from different angles and with variety of methods. The final Portfolio contained eight primary research studies, examining the experience of all, or specific groups of, older people and staff; and three secondary, or desk-based, studies exploring definitional and methodological issues and assessing the available data sources.

The evidence-base from the combined PANICOA studies is extensive, drawing on over 2,600 hours of observation and just under 500 individual or group interviews in 32 acute hospital wards and 42 care homes. Together the studies involved a range of different types of care provider and geographical locations across the UK, although largely in England and Wales.

The PANICOA research provides insight into the frequency of different types of abuse and gives an indication of the overall balance of care (of good or bad treatment) in the homes and wards studied. The high level of correspondence (or 'read across') between the main findings of the different studies suggests that they are likely to be broadly indicative of the situation in care homes and hospitals more widely.

THE PANICOA FINDINGS

The findings of the individual PANICOA studies were brought together into a series of 'Narratives', providing four different 'ideal-typical' perspectives on the institutional care experience:

From the patient/resident perspective:

- there was little evidence of actual physical harm, but harm arising from institutionalised forms of neglect, or serial omissions of care, was notable;

- the experience of neglectful or disrespectful treatment and of 'psychological harm' was also evident, with patronising or 'infantilising' communication ('elderspeak') being prevalent, particularly in hospitals;

- the lack of privacy and dignity in personal care, especially around using the toilet, was a reliably negative experience;

- basic 'hands on' care was generally good, at times excellent, although suffering from inadequate resources (clean linen, adapted cutlery) and pressures of time, in both hospitals and care homes;

- there were risks from physical environments that were not purpose built for highly dependent older people;

- the most significant feature of the care experience was the variability and unpredictability of its quality, even in a single site on a single day;

- while most sites had formal complaint systems, there were fewer opportunities for informal discussion of concerns or ways to report mistreatment arising from 'normalised' organisational practices.

From the care staff perspective:

- the general experience of care staff was not generally good, with evidence of considerable work-related stress and an 'everyday' risk of verbal or physical injury for some on the front-line of care;

- staff were committed and hard working but felt hampered by inflexible or 'risk-averse' organisational systems that reduced the potential for professional judgement or individual initiative;

- staff were generally keen to develop their skills and capabilities but the opportunities to do so were limited and typically considered unsatisfactory;

- the overall level of job satisfaction was low, but higher for nurses than health/care workers;

- the skills required for work in a multicultural context, and the particular challenges faced by minority ethnic staff, were not seen to be adequately recognised;

- there was an underlying atmosphere of anxiety and blame; managers were viewed as lacking understanding of the daily pressures staff faced and not fully supportive if things went wrong.

From the care provider perspective:

- the changing demographics of their care populations were resulting in the need to maintain higher-risk institutional care environments;

- financial constraint across the health and care sector was seen to be putting pressure on resources especially in care homes with large numbers of publicly funded residents;

- recruitment and retention problems, resulting in greater use of temporary or agency staff, were increasing workload management pressures;

- care commissioners were seen generally to underestimate the greater constraints under which care providers were working;

- variability and inconsistency in the requirements of care regulators (at least in England and Wales) were making it difficult to plan effectively for the future;

- innovation and initiative were seen to be hampered by safeguarding processes that were not proportionate to the level of risk involved;

- both regulators and safeguarding bodies were viewed as focusing more on apportioning blame than on providing support and assisting development;

- care home providers, in particular, tended to feel that their work was not well understood, or always fairly regarded, by government, regulators or the public more widely.

The wider care community:

A fourth Narrative was also evident in the PANICOA findings, illuminating the relationships between the different organisations with (various) responsibilities for the care and protection of older people in institutional contexts (such as regulators, commissioners, safeguarding agencies, national health and care bodies and educators):

- there was considerable 'disconnect', or lack of 'read across', between the systems and practices of the main bodies and agencies in the field, particularly between the NHS and other relevant parts of the institutional care community;

- the collection and exchange of data on elder mistreatment was unsystematic and largely uncoordinated, beset by a lack of consensus on the definitions of key terms, such as 'neglect' or 'harm';

- the distinctive roles played by the wide range of bodies involved in different ways in safeguarding at local and national levels were not always mutually clear, nor operationally consistent;

- there were evident tensions surrounding joint work, arising from issues such as funding arrangements and fee structures, and regulatory and safeguarding practice.

CONCLUSIONS

On the care service:

The messages from the PANICOA research highlighted the areas of the care experience in need of policy and practice attention. Those areas with the strongest correspondence (read across) between the individual studies included:

- identifying and preventing harm resulting from ongoing 'systemic' forms of neglect, including delays and omissions of care, and from the risks created by unsafe or inappropriate physical environments;

- improving performance on providing privacy and ensuring dignity in all areas of personal care, most especially in using the toilet;

- preventing or addressing disrespectful and ageist attitudes, particularly in hospitals which must become more systematically 'attuned' to the needs of older people as their single largest patient population;

- securing regular and detailed feedback from residents/patients, and their relatives/visitors, on all aspects of the care experience, including the environment, and ensuring that this feedback is routinely used by care provider organisations, with clear demonstration of the actions taken as a result;

- (for those in care homes) developing further ways to maintain the social and community engagement of residents and to support them to retain a sense of purpose and meaning in their lives.

On the care culture:

The nature of an organisation's culture (or behaviour) emerged as a strong determinant of the quality of the care experience, for both staff and patients/residents. The latter were more likely to be treated with respect and dignity by staff who were treated in the same way by their colleagues and organisations. The Narratives thus highlight the strong 'mutuality' or reciprocity that exists between the interests of staff and those for whom they care and indicate the benefit to the care organisation likely to be derived from greater investment in its human resource.

The PANICOA studies revealed the inherently volatile nature of organisational cultures and their ability to shift markedly in the face of change. Specific areas of organisational action (or inaction) could be particularly sensitive 'shift-points' – capable of decisively nudging the internal culture in a positive or negative direction. For a safe and respectful organisational

culture, the management of workload pressures and the response to neglectful or disrespectful behaviour were identified as two important shift points.

On working together:

The PANICOA research highlighted many areas of tension or 'dissonance' between the different operating parts of the wider 'institutional care community'. Despite the strong common purpose that existed between these different 'stakeholders' and the shared challenges they faced, there was very limited collective work to support or strengthen core parts of the system (such as care staff) or areas of activity, such as safeguarding data). This leads to the final conclusion about the positive role that a stronger sense of common purpose or 'mutuality' could play across the care community, encouraging the collective investment of time or resources in areas likely to deliver clear 'value-added' for all involved.

The main Report concludes with recommendations for a set of **Next Steps** designed to strengthen the influence of mutuality and encourage collaboration and cooperation. These cover actions for a range of different 'stakeholders', across three broad areas:

- developing the capability, and increasing the stability, of the health and care workforce, particularly frontline staff and ward/home managers;

- stimulating and supporting the cross-fertilisation of ideas and innovation across (and within) health and care home sectors, especially on good safeguarding practice;

- establishing a stronger 'connectivity' of systems, standards and information (especially in respect of data sources) across the institutional care community, particularly between regulators, commissioners and safeguarding bodies.

In addition to the Next Steps, the main Report has drawn on the findings and key messages of the PANICOA studies to develop two **Templates for Good Practice**, designed to support, or improve where necessary, the development of a safe and respectful care service and care culture in care homes and hospitals. The studies themselves have also produced a series a practical tools and guidance to assist both practice and research in institutional care contexts. These **'PANICOA Products'** and the summaries of the individual research studies are provided as **Annexes** to the main Report.

SECTION 1: THE PANICOA PORTFOLIO

The PANICOA Portfolio contains a total of eleven different research studies, commissioned over a four-year period from 2008 to 2011. The individual studies examined the issue of the mistreatment of older people in care homes and hospitals from a range of different angles and using a variety of methods. Individual research studies, whatever their strengths or ambition, are only likely to reveal a particular dimension or 'slice' of the reality. The idea of the Portfolio was to combine a range of studies, with different and complementary strengths, to produce a more complete and rounded view of this complex problem.

Some of the studies involved 'secondary', desk-based research, designed to assist subsequent "Empirical" investigations in care homes and hospitals. These examined the difficult definitional issues surrounding key concepts such as abuse/neglect/loss of dignity (Dixon et al., 2009), the relationship between definitions and prevalence estimates (Biggs et al., 2009) and the quality of existing relevant data sources (Manthorpe et al., 2011).

Others undertook in-depth primary research on the experience of both staff and patients/residents in hospitals (Tadd et al., 2011a) or care homes (Tadd et al., 2011b), or examined that of particular groups, such as health care assistants (Schneider, 2010), or older people with advanced dementia (Brooker et al., 2011) or from black and minority ethnic communities (Bowes et al, 2011). Three studies: O'Mahony et al., 2013 and Killett et al., 2011 and 2013, gave particular attention to the role of organisational culture in the care and protection of older people.

In combination, the PANICOA studies provide a substantial evidence base, involving investigation of the views and experiences of a wide range of participants in a total of 32 acute hospital wards and 42 care home sites across the UK. This involved the following data collection activity:

- 2,644 hours of observation, including around 600 hours of participant observation;

- 271 individual interviews with care staff, including 48 managers;

- 265 interviews with residents/patients, including 66 family members/care givers;

- 34 interviews with other stakeholders, such as care providers, regulators, policy makers, commissioners and user group representatives;

- 23 group interviews/focus groups with care staff, including geriatricians.

The main findings of the individual PANICOA studies have been drawn together to provide a combined evidence base for this Report. In summarising the data, greater weight was given to findings that were supported by at least one other study. A full list of the studies is provided opposite, and more detailed summaries of each can be found in **Annexe 2**. Between them, they have produced a wide range of 'products' (tools and guidance) to assist research and practice in institutional care contexts. Details of these are provided in **Annexe 3**.

Report date	Author & Title	Abstract	Method	Research type ▼
2009	Biggs, S., Erens, B., Doyle, M., Hall, J. and Sanchez, M. Abuse and Neglect of Older People: Secondary Analysis of UK Prevalance Study	Estimates of the prevalance of mistreatment of older people based on the UK Study of Abuse and Neglect of Older People	secondary analysis of survey data, using multivariate logistic regression	secondary
	Dixon, J., Biggs, S., Tinker, A., Stevens, M., and Lee, L. Abuse, Neglect and Loss of Dignity in the Institutional Care of Older People	Discussion of the issues of 'meaning and measurement' in the definitions of abuse, neglect and mistreatment of older people	desk-based review of policy, practice & academic literature	secondary
2010	Schneider, J., Scales, K. and Lloyd, J. Challenging Care: The Role & Experience of Health Care Assistants in Dementia Wards	Exploration of the subjective experience of staff who work directly with older people with dementia	'collaborative' ethnography, using participant observation from multiple perspectives in eight assessment wards	primary
2011	Bowes, A., Avan, G. and Macintosh, S. Dignity and Respect in Residential Care: Issues for Black and Minority Ethnic Groups	Exploration of the perspectives of older people from black and minority ethnic groups on issues of dignity, neglect and abuse	interviews and non-participant observation in seven care home sites	primary
	Brooker, D., La Fontaine, J., De Vries., K. and Porter, T. How Can I Tell You What's Going on Here? Bringing to Light the Perspectives of Residents with Advanced Dementia in Care Homes	The Development of PIECE-dem: An observational tool designed to identify risk & preventative factors for abusive, neglectful or disrespectful care	individual and group interviews in seven trial sites	primary
	Killett, A., Burns, D., Hyde, P., Poland, F., Gray, R. and Kenkmann, A. Organisational Dynamics of Respect and Elder Care	Examination of the impact of the organisational features of care homes on respectful care practice with older people	comparative ethnographic case studies in eight care home sites	primary

Report date	Author & Title	Abstract	Method	Research type
2011 Continued...	Manthorpe, J., Stevens, M., Hussein, S., Heath, H. and Lievesley, N. The Abuse, Neglect and Mistreatment of Older People in Care Homes and Hospitals in England	Identification and comparison of the method and content of existing data collections on elder abuse	desk research and interviews	secondary
	Tadd, W., Hillman, A., Calnan, S., Bayer,T. and Read, S. (2011a) Dignity in Practice: An Exploration of the Care of Older Adults in Acute NHS Trusts	Exploration of the extent to which dignity is maintained in the care of older people in acute hospital wards	interviews and non-participant observation in sixteen acute wards in four hospital sites (two for older adults and two for adults of all ages)	primary
	Tadd, W., Woods, R., O'Neill, M., Windle, G., Read, S., Seddon, D., Hall, C. and Bayer, T. (2011b) PEACH: Promoting Excellence in All Care Homes	Development of evidence-based guidelines for policies and practice in care home regulation, workforce training & protection of vulnerable adults	individual/group interviews, surveys and non-participant observation in eight care home sites; piloting of training package in seven sites	primary
2013	Killett, A., Bowes, A., Brooker, D., Burns, D., Kelly, F., La Fontaine, J., Latham, I., O'Neill, M., Poland, F. and Wilson, M. What Makes a Real Difference to Resident Experience? Digging Deep into Care Home Culture: the CHOICE Research Report	In-depth examination of organisational cultures that inhibit or encourage the provision of high quality care for older people in residential and nursing homes building on earlier PANICOA studies	in-depth ethnography using structured observations in twelve case study sites	primary
	O'Mahony, S., Sanchez, A., Hunt, J. and Tadd, W. Organisational Culture Underpinning Excellent Care vs Harm and Neglect in The NHS: A Feasibility Study	Assessment of the best ways to measure the treatment of older people in hospital and exploration of the organisational factors that promote high quality care of older people	individual and group interviews and non-participant observation in nine hospital wards in three Trusts	primary

SECTION 2: DEFINITIONS AND DATA

WHAT IS MISTREATMENT?

The PANICOA initiative used a broad definition of mistreatment that included the key concepts of 'abuse', 'neglect' and 'loss of dignity'. As in the earlier community prevalence survey (O'Keeffe et al., 2007), abuse was divided into 'sexual', 'physical' and 'psychological' (financial abuse was not covered.) On one level these concepts appear to have a generally accepted 'everyday' meaning. On another level it is clear that when we try to put them to use, they can be difficult to pin down precisely.

Both the observation and the 'felt experience' of mistreatment are highly subjective, influenced by a range of, often unacknowledged, values and assumptions on the part of both 'viewer' and 'viewed'. Much is dependent on agreed and acceptable thresholds of acceptability for particular behaviours and/or the specific context in which they occur. What may be an accepted characteristic of an informal relationship with family members or friends, for example, may be highly inappropriate in a formal care relationship with professional staff.

It is also the case that the same action may produce contrasting reactions on the part of different residents or patients. Older people are not an homogeneous group and will have very different tastes and preferences. Some may like to be addressed with 'endearments' such as 'love' or 'darling', for example, while others may feel this form of communication undermines their sense of dignity. Whoever is involved, and this includes researchers and analysts, judgements about the acceptability of particular behaviours will be influenced by personal factors such as age, sex, culture, race and/or class, and by organisational and professional standards of practice.

It is vital that we secure some clarity and agreement on the 'applied' meanings of these core concepts if we are to establish a sound evidence base for policy and practice. One of the initial 'preparatory' PANICOA studies (Dixon et al., 2009) therefore set out to examine the difficult definitional and conceptual issues involved in collecting evidence on abuse and neglect in institutional settings, in order to inform the work of the subsequent empirical studies in the Portfolio, as well as to facilitate future research in the field.

Dixon et al highlight the 'conceptual slipperiness' of the terms involved in the idea of mistreatment with the result, they argue, that many existing definitions are *'… vague, subjective and imprecise'* (2009:iii). They also have potentially very different meanings in an institutional as opposed to a community context. While the concept of abuse (and its subdivisions) could be used *'…with minor adaptations'* in a residential context, they suggest the concept of 'neglect' is more problematic - tending to be 'over-inclusive' and extremely susceptible to subjective interpretations. Arguably, the idea of 'loss of dignity' is even more slippery.

In understanding the causes of mistreatment, especially of neglect, an institutional context may bring additional factors into play. In particular, mistreatment may be the result of organisational rather than individual 'behaviour' and involve omissions of care rather than (or as well as) intentionally abusive or disrespectful actions. It may be difficult to identify a single 'perpetrator' and unclear about who should have provided the assistance, as systemic organisational factors may play a direct and influential role in the failure to provide adequate care. Dixon et al

argue that this indicates that the 'person-to-person' model of mistreatment may be less significant in institutional than in community contexts.

Dixon et al suggest that an essential attribute of an incident of mistreatment, in whatever context, is that it will involve a breaking of 'trust' with the older person. Recognising the highly subjective nature of the concept of 'trust', they propose the more specific notion of a 'position of trust'. Here, mistreatment takes place in the context of a relationship between the older person and someone with *'...a recognised obligation or duty towards someone in a less powerful position'* (Dixon et al., 2009 ii). Unlike the more general concept of 'trust', Dixon et al argue that the idea of a 'position of trust' is fairly straightforward to use, being *'...transparent, robust and operationalisable'* (ibid).

They argue that the concept also works in an institutional setting because the position of trust can involve the relationship that the older person has with a professional/paid carer, or with the wider care provider who, as the 'registered person', has *'...clear organisational responsibilities to ensure quality of care'* (Dixon et al 2009:vi). Other residents/patients and family members can be, but are not necessarily, placed in a position of trust. Dixon and colleagues suggest the usefulness of the idea of 'circles of trust', which can be broadly or narrowly drawn.

A narrow circle of trust would include family members providing informal care or other support (such as management of affairs), with the outer circle involving the older person's wider family and friendship group. In an institutional setting, the outer circle should also include all visitors to the home/hospital although (perhaps more arguably) not other residents or patients. Dixon et al acknowledge that physical and mental harm, to staff as well as patients/residents, from the behaviour of other residents or patients/residents has been found to be associated with generally higher levels of reported abuse, but they argue that it is sufficiently distinctive, in

causes and consequences, to be reported as a separate phenomenon. This is not least because residents or patients would not typically be seen to be operating in a position of trust to one another.

A second key attribute of an act of mistreatment, Dixon et al argue, is 'intentionality'. This suggests that there has to be an intention to mistreat on the part of the perpetrator in order for there to be an identifiable case of 'mistreatment'. They acknowledge the centrality of the experience of the older person him/herself, whatever the intention on the part of the perpetrator. However, they suggest that, in some cases, this could lead to practitioners or organisations being held to *'...unclear or aspirational standards that it may be unreasonable to expect of them, or their organisation* (2009:26).

Referring to the concept of 'reasonable standard of care', as set out by the Department of Health in *'Independence, Choice and Risk'* (2007), they conclude that there needs to be a '...balance of concern' between the intentions of the perpetrator and the impact on the victim. Behaviour should only be considered mistreatment, they argue, if it occurred in a situation where *'...the perpetrator knew, or could reasonably have been expected to know, that their action or inaction would or could cause harm'* (Dixon, 2009: ii). Ascertaining 'intent' or wilfulness on the part of a particular individual, however, may not always be easy, particularly if it has to be established in the context of disciplinary or criminal proceedings. And, of course, the idea of 'reasonableness' is itself conceptually 'shifty'.

In institutional care settings, the issue may be less about the intent on the part of an individual and more about the (possibly unintended) consequences of institutional systems or actions. Dixon et al suggest that the idea of 'intentionality' should be broadened to cover not only organisational 'knowledge' of the impact of the standard of care provided but also the failure on the part of the organisation/staff member to acquire that knowledge.

For example, Killett et al (2013) highlight the way in which harm can result from the lack of information-sharing within an organisation, citing the case of an elderly person who had a fall as a result of some staff not being informed that she could not walk safely in her slippers. This issue is central to the current debate about the idea of 'corporate accountability', whereby the 'intentionality' of an action or inaction may be considered inherent in the concept of the organisation's 'duty of (intention to) care'.

HOW CAN MISTREATMENT BE MEASURED?

While acknowledging the highly contestable nature of the concepts involved in understanding 'mistreatment', Dixon et al suggest that they can be *'adequately and defensibly'* explored if researchers focus on areas where there is most agreement and on specific aspects of care that can be observed and measured, such as hydration and nutrition, physical handling, privacy and using the toilet. It is important, they argue, for operational definitions to be as specific, concrete and unambiguous as possible, so that agreement can be reached about exactly what is being observed/recorded. **Annexe 3A** provides a summary of their methodological advice for researchers working in the field.

Dixon et al argue that distinctions should be drawn between observed or recorded events and the subjective response to them (e.g. being made to feel worthless or a nuisance), on the part of the subject. In general, they suggest, research should focus on those areas where the subjects are most likely to be able to provide *'accurate and robust information'* about what happened to them and focus on behaviour or actions that most people would agree constitute *'…relatively unambiguous examples of mistreatment'*. They have produced a detailed list of the observable behaviours that could constitute potential mistreatment in an institutional context in **Annexe 3B**.

HOW MUCH MISTREATMENT IS THERE?

Answering this question depends crucially on how wide the net is cast around the older person and on the extent or frequency of a particular abusive or neglectful action. While some 'one-off' actions, such as verbal or physical abuse of a resident/patient, will be clear evidence of mistreatment, other acts (or inactions) - such as failure to change bed linen promptly, or to address a person by his/her right name - may arguably only be seen to constitute 'mistreatment' if displayed consistently and frequently over time. Where the focus is on the manner in which a 'legitimate' action (washing or dressing, for example) is carried out badly, Dixon et al argue that 'qualifiers', such as 'excessive' 'unnecessary' or 'roughly', may need to be used. The problem, of course, is that these terms bring additional problems of interpretation and quantification, which will need to be addressed.

A second PANICOA study (Biggs et al., 2009) examined the impact of different definitions of mistreatment on the identification of prevalence and risk by reanalysing the initial community survey data (O'Keeffe et al., 2007). As we would expect they found that prevalence is lower if restricted to the 'inner circle' of family and friends and greater if extended to the 'outer circle' of friends and acquaintances. It also varied crucially according to whether single or multiple incidents of mistreatment were included. The issue of the frequency of a particular action (or inaction) is particularly relevant to understanding less clearly defined types of mistreatment, such as neglect or psychological abuse and to identifying more 'normalised' forms of organisationally-driven mistreatment.

The original community survey used a relatively narrow definition of mistreatment, involving only 'inner circle' perpetrators (family members, friends or care worker(s)) and single incidents of financial, sexual and physical abuse. It also introduced a threshold for neglect and psychological abuse of ten or more incidents. Biggs and team applied a much broader definition to the same data that included a wider circle of trust and single incidents of any type of abuse.

The result of applying these different definitions of mistreatment was, not surprisingly, starkly different estimates of the prevalence of 'mistreatment'. For older people living in the community the incidence was found to range between 1 in 40, when using the narrower baseline definition, to almost 1 in 10 when using the broader definition. Clearly, how much you find depends crucially on how you define what you are looking for.

The issue with the use of a frequency threshold (as in the 10+ incidents in the baseline definition above) is that it may serve to exclude one-off less serious incidents. And, of course, everything will depend on how and by whom the judgement of 'serious' is reached. However, Dixon et al argue that thresholds may be particularly useful in an institutional context as they can encompass the cumulative effects of repeated 'low-level' harms. Numerous, but less immediately serious, incidents of neglect and psychological abuse are more likely to indicate systemic failings and poor care standards, suggesting the need for 'organisational remedies' rather than actions against particular individuals.

WHO IS MOST AT RISK?

On the basis of their re-analysis of the community survey, Biggs et al found that, generally speaking, the risk of mistreatment is higher if the person is female, separated or divorced, is experiencing depression (or has in the past), has poor quality of life and regularly uses medication. Age, in and of itself, was not found to be a significant risk factor for older people in their own homes but was associated with many of the other factors that were seen to increase the likelihood of mistreatment, such as loneliness, depression, ill-health and physical dependence.

However, the influence (strength) of different risk factors, and the relationship between them, was found to vary with the different definitions of mistreatment used. As we have seen, the broader the definition used, the larger the 'mistreated group' becomes. But as the size of the

group expands, the number of *significant* risk factors reduces, as does the likelihood of those factors occurring. The sex of the older person, for example, was found to be a significant factor with the narrower 'baseline' definition, but not at all significant with the broader definition. Only 'marital status', 'depression', 'quality of life' and 'use of medication' remained significant risk factors for mistreatment, whatever the size of the 'mistreated group'.

Different types of mistreatment were seen to share 'core' risk factors, although the way in which these factors interacted was complicated. 'Loneliness', 'use of care services' and 'marital status' were associated with both financial and physical abuse, for example, but financial abuse was linked with being single or widowed, and physical abuse with being separated or divorced. Again, while financial and physical abuse were 'positively' associated with use of care services, there was a negative association between service use and psychological abuse. As Biggs et al conclude, their findings point to *'...a phenomenon that is complex, multi-faceted and sensitive to different perspectives'* (2009: 6). Different forms of mistreatment have different 'dynamics' and, they suggest, the policy/practice response needs to be similarly differentiated.

Finally, at least for older people living in the community, it was not found to be the case that experiencing one kind of mistreatment would increase the likelihood that they would also be subject to others. Biggs et al found less than one in ten reporting more than one type of mistreatment and only a *'small proportion'* indicating that there had been two different types of perpetrator involved. However, given the combination of risk factors surrounding older people in institutional care - particularly those with dementia and other neurological conditions - it is likely that the risk of multiple mistreatment will be significantly greater. As Dixon et al comment on care home residents: *'...as intensive service users, they will also be more vulnerable to service failure'* (2009:iii).

WHERE ARE THE DATA?

A final preparatory study in the PANICOA Portfolio examined the existing sources of data on the incidence of abuse, broadly defined to cover neglect and mistreatment (Manthorpe et al., 2011). **Fig 2** (below) shows the wide variety of data sources relevant to the safeguarding of older people in hospitals and care homes. Even in combination, however, the data from these various sources fail to provide a clear national picture of the nature or volume of elder mistreatment. Indeed, it would be impossible to combine the data from these diverse sources, given how much they vary in the definitions/methods used and in the quality or consistency of the data collected. As Manthorpe et al conclude from their overview of the available evidence: '*...data are scarce and limited, definitions and collection are unsystematised centrally and locally, and currently demand collation from various and disparate sources'* (2011:i).

Manthorpe and colleagues suggest that this fragmented 'data picture' results from the lack of a shared strategy for data collection on elder abuse and mistreatment in institutional settings. They call for better 'link-up' of relevant data across government departments and greater co-operation in developing the potential of existing data sources. However, they also warn that collecting better data is not an end in itself but should be seen as an opportunity to learn lessons to prevent abuse and to enhance the rights of older people. The problem with the focus on adverse event data is that it engenders a culture of uncertainty and blame, in which we are much less likely to come together to identify the shared learning.

Manthorpe and colleagues argue that the focus on adverse event data also has the effect of reinforcing the view of older people as powerless and in need of 'rescuing'. If we are fully to understand the causes and costs of mistreatment, and the complex situations in which they occur, we need to draw strongly on the direct experience of older people, with their active engagement wherever possible.

To engage older people more effectively, however, we need to develop the methods to facilitate this - particularly with those who may find it difficult to speak for themselves. Another PANICOA study (Brooker et al., 2011) aimed to contribute to this process by developing ways to facilitate the inclusion in research of people with advanced dementia. Although in need of final refinement, it is hoped that the resulting observational approach, "PIECE-dem", will be able to identify both supportive and neglectful practice and be of use not only to researchers but also, importantly, to staff in monitoring and reducing the risk of mistreatment in the care setting.

CONCLUSION

The PANICOA studies discussed above were completed between 2009 and 2011. There has been significant change since this time, both in the 'organisational architecture' of health and care services and what is now known as 'adult safeguarding'. Manthorpe et al provide a summary update of the main policy statements and actions relevant to care homes and hospitals from the time of the research to the present day (**Annexe 3C**) - a process they describe as '*...adult safeguarding coming of age'*.

However, it is not clear how much of the more recent policy activity has focussed on strengthening the safeguarding evidence-base. As Brooker et al comment: "*...while current strategies, initiatives and guidance all seek to improve care practices...none have identified or sought to identify the prevalence of abuse, neglect or loss of dignity'* (2011:16). Developing the evidence will require greater cooperation and coordination between data gathering sources – a real and urgent challenge given the current 'system turbulence' within the health and care sector and the policy shift towards greater localism.

FIG 2: THE SAFEGUARDING DATA JIGSAW

data from **care regulators**, including focussed reports from CQC, but individual - level data only

individual studies of the experience of older people in care homes/hospitals in UK **National Data Archive**, but none to date cover mistreatment in institutional care

National Information Centre for Health and Social Care **Abuse of Vulnerable Adults** (AVA) referrals - good source data covering hospitals and care homes, but future uncertain

annual reports from **Adult Safeguarding Boards**, but data unsystematic and variable in quality

N**HS Incident Reporting Systems,** annual staff surveys and NHS involvement in **National Confidential Enquiry systems** potentially extensive, but not confined to abuse and neglect

reports from **Mental Capacity Advocate Services** to DH, but small in size and limited in coverage

published reports from **professional regulators**, but none indicate age and only NMC identifies nature and location

lists held by **the Independent Safeguarding Authority** of referred/barred adults provides details of the incident and perpetrator, but little on the 'victim'

data on **complaints and inquiries**, including both case studies and more system-wide overviews, but while **Serious Case Reviews** have potential, their use is limited by variable formats and thresholds

information from the **telephone hotlines** of Action on Elder Abuse (AEA), but only on individualised case data

Based on Manthorpe et al., 2011

(Further details of text in **bold** can be found in the Glossary)

NMC = Nursing and Midwifery Council

CQC = Care Quality Commission

DH = Department of Health

SECTION 3: THE PANICOA FINDINGS ON A 'RESPECT AND PROTECT' CARE SERVICE

This Section examines the findings of the PANICOA studies, taken together, against a conceptual framework created by the authors of this Report. **The PANICOA Framework** drew on the experiences and views of the older people (and relatives and friends), care staff and managers presented in the studies, and on selected texts, to identify eight central aspects, or 'domains', of the overall care experience. The areas covered by each of the domains are set out in the Box below:

THE PANICOA FRAMEWORK

domain 1: direct care primary

Covers the assessment for, and provision of, basic 'hands-on' or 'fundamental' personal and health care, including its accessibility, appropriateness, quality and timeliness. It ranges from very basic nutrition and hydration through to infection control. It does not cover medical interventions. The domain also covers the nature of the staff providing care, including their number, skills, training and development/support, as well as the care provider's systems for quality monitoring, control and regulatory compliance.

domain 2: safety and security

Covers the protection from the risk or threat of abuse, neglect or harm on the part of those being cared for and the security of their personal possessions and records. It includes the 'Sense of Security' (Nolan et al., 2006): feeling able to express views, concerns or complaints without fear of reprisal. It also covers the safety and security of staff, including unacceptable work-related stress as well as the safety of the physical environment/equipment provided by the care organisation and systems for risk assessment and response.

domain 3: dignity and respect

Covers the manner in which older people in institutional care are treated, including, most centrally, in the privacy given to the person/affairs and the respect accorded to their personal beliefs, values and customs. It also covers the treatment of staff providing care/support, by both residents/patients and managers/employers, as well as the care organisation's systems for ensuring an 'operational culture' of dignified and respectful care.

domain 4: continuity and coordination

Covers a key dimension of person-centred care – its 'connectedness', both for the individual patient/resident over time ('longitudinal continuity') and between the different staff and organisations providing care ('horizontal continuity', Winchcombe, 2012). The relationships between staff and residents or patients is a central focus ('relational and therapeutic continuity') as are the relevant organisational systems ('management continuity' and 'information continuity') of the care provider (Winchcombe, 2012).

domain 5: involvement and control

Covers the degree of involvement that residents/patients have in decisions about their care and treatment; the 'Involve me' dimension of a personalisation approach (Owen and Meyer, 2012) and, more generally, the extent of their 'personal agency', (Winchcombe, 2012), covering the degree of control they have over their context and circumstances and the extent to which they are able to retain, or regain their social and physical independence.

domain 6: communication and information

Covers the content of the information and advice that is provided to residents/patients and their carers/relatives about their care, their care choices and care providers. It also covers the forms of communication being used, its clarity and accessibility, especially for those who have special communication needs/requirements. The lines of communication between staff within the care organisation and between the organisation and its external 'care partners' are also in focus here.

domain 7: community and relationships

Relates to the 'Connect with me' dimension of the *'My Home Life'* personalisation themes (Owen and Meyer,2012) : the importance of developing meaningful relationships, both with other residents/patients and contacts outside the institution and with care staff. It involves the 'Sense of Belonging' (Nolan et al., 2006): the ability to feel 'part of things', both within the home/hospital and the wider community, and to maintain existing relationships or form new ones. It also covers the relationships between care staff and between the care organisation, its local community and relevant care bodies (e.g. providers/regulators).

domain 8: identity and meaning

Covers the maintenance of identity or 'selfhood' on the part of older people - the 'See who I am' dimension of personalisation (Owen and Meyer, 2012), including their personal history or 'life/social continuity' (Winchcombe, 2012). It also covers their sense of having a contribution to make in life - their 'Sense of Purpose' and 'Sense of Achievement' - the ability to achieve their goals or be satised with their efforts (Nolan et al., 2006). The 'Sense of Significance' is also covered here: the extent to which older people are able to feel that they matter and that their life has importance (Nolan et al., 2006).

MAPPING THE FINDINGS AGAINST THE PANICOA FRAMEWORK

In the following pages, the findings from the PANICOA studies are mapped across the eight care domains of the PANICOA Framework. For each domain, the performance of care providers is assessed against an overall aspiration for that aspect of care, based on existing policy, standards and guidance, see **Annexe 3D**.

THE CARE ASPIRATION:

Residents/patients receive good quality 'hands-on' care in the areas of continence, bladder and bowel care, personal and oral hygiene, nutrition and hydration, pressure area care, cleanliness of self and surroundings, infection control, and relief of pain,

provided by health and care staff who are appropriately skilled and qualified with knowledge of the particular needs of older people, especially those living with dementia or other capacity limitations, who are well managed and receive relevant and up-to-date training, development and support,

in organisations that provide a well-managed environment with effective quality systems and sufficient resources, including 'frontline' staff and managers.

THE PANICOA STUDIES FOUND:

Residents/patients stressed the importance of good direct care, with some patients seeing the failure to provide for fundamental needs as a form of neglect and abuse. No patients considered that they had experienced service failure, however, and on balance the PANICOA evidence indicated that there was predominantly good, at times excellent, basic care being provided in both hospitals and care homes, including for people with complex needs.

However, the evidence also reveals areas of direct care that appeared to fall short of an overall good standard, including delays in meeting physical and/or psychological needs and inconsistency in the quality of care provided. Being able to use the toilet was a particular concern, involving *'…considerable areas of anxiety'* (Killett et al., 2013: 31) for care home residents, despite the organisational attention this issue has received. Many older people, particularly from minority ethnic communities, appeared to have relatively low expectations about the standards of basic care and, in hospitals, there was evidence that older people tried to be 'good patients' and not ask too much of staff. Some relatives of care home residents considered that the regulatory standards and frequency of inspection visits were set too low.

Health and care staff were generally seen to be hardworking and committed to the principles underlying good basic care, in particular that it should be person-centred and 'process' as well as 'outcome' focussed. There was a common perception, however, that the ability of staff to provide good direct care was at times (possibly increasingly) constrained by low staffing levels and limited resources, such as adapted cutlery or walking aids.

In hospitals, the lack of clean bed linen was seen to be a *'...daily concern'* for many ward staff (Tadd et al., 2011a: 248).

In both hospitals and care homes, there was evidence that much of the basic 'hands-on' care work was being undertaken by (or delegated to) less experienced and lower-qualified staff. Hospital nurses were seen to be unwilling to undertake personal care tasks, such as help with using the toilet or cutting toenails, and health care assistants had, possibly as a result, assumed significant responsibility for the care of older people, often exceeding the terms of their formal job descriptions. Typically they were seen to perform these tasks with *'...warmth, empathy and commitment'* (Schneider et al., 2010: 91).

There was general agreement that hospital staff at all levels needed more and/or better training in the care of older people, especially for patients with dementia or other complex care needs. There was widespread concern about the lack of a basic entry qualification for the care home sector. In both care sectors, staff appeared keen to undertake more training, and being trained was associated with more positive approaches to care. There was general dissatisfaction with existing training opportunities, however, and a sense that these tended to be directed at more highly qualified staff.

Care organisations were seen to be experiencing considerable pressure on human and other resources. Care homes accepting large numbers of publicly funded residents appeared to be facing particular challenges in this respect and the general difficulty in recruiting suitable staff was reported to be worsened by the lack of a recognised pay or career structure across the sector. In hospitals the constraints on ward budgets were seen to have led to *'...untenable staffing levels'* (Tadd et al., 2011a: 245).

In both care contexts, high staff turnover, with the consequent use of temporary or agency staff, was seen likely to encourage a more 'task-based' approach

and a fragmented care experience. This tendency, moreover, was frequently felt to be compounded by a regulatory focus on documentation and 'ticked boxes' rather than on the quality of the care provided.

safety and security

THE CARE ASPIRATION:

Residents/patients are effectively protected from the risk of abuse, neglect or harm and receive care/treatments/ medicines in a safe way; are able to express their views/concerns without fear of repercussion and have confidence that their belongings and personal records will be kept secure,

by health and care staff who are themselves free from the risk of harm or abuse, bullying or unacceptable work-related stress, who are aware of, and compliant with, their roles and responsibilities under health and safety legislation and feel safe to raise concerns or identify problems,

in organisations that provide a safe physical environment with suitable and well-maintained equipment, and training in its use, operating effective risk assessment/monitoring systems, appropriate health and safety/security procedures, and transparent and accessible complaints systems.

THE PANICOA STUDIES FOUND:

Residents/patients and their relatives saw 'safety' and 'security' as two of the most important aspects of institutional care. While there was no direct observation in the PANICOA studies of physical aggression by staff towards residents or patients, there were reports of mistreatment, especially of minority ethnic

older people, occurring in 'other' care organisations. The risk of harm from other residents in care homes however was identified as a *'...prevalent and problematic phenomenon'* (Tadd et al., 20011b: 256), and one feared by some prospective residents. A few instances of abuse of residents/patients by relatives/visitors were also reported by staff.

Personal risks were also identified in the physical environment, particularly for older people who were frail and/or confused. These included restricted space, slippery floors, poor lighting, lack of water temperature control, inadequate signage and, in hospitals, large and complex equipment. Overall, residents and patients, again especially from minority ethnic communities, generally appeared reluctant to articulate problems or challenge poor care. Some patients and relatives reported hostile or defensive responses from hospital staff when they did raise concerns and a reluctance to address these informally, at least initially, at ward level. And there was anxiety in care homes that voicing complaints could result in being asked to move, or in the home being closed.

Health and care staff in both hospitals and care homes were found to be at risk of verbal and/or physical aggression, including racism, from those for whom they cared. In particular, the risk to health care assistants was reported to be such that *'...physical pain and possible scars'* (Schneider et al., 2010:13) were an intrinsic and accepted part of the job. There was also evidence of health and care staff experiencing work-related stress, due largely to perceived shortages of human resources. This was reported as having led in some cases to staff *'...cutting corners to get the job done'* (Tadd et al., 2011b: 132).

There was evidence of emotional exhaustion or 'burn-out' on the part of frontline staff, particularly due to workload pressures. This feeling of stress was compounded, especially in hospitals, by the fear of making mistakes or being blamed when things went wrong. Staff were not seen to be *'...passive victims',*

however, and appeared able to adopt '…sophisticated strategies' (Schneider et al., 2010: 82) to manage or minimise work-related stress, particularly through the development of a strong team identity. However, this could be at the cost of a more detached attitude to those they cared for and/or to a more defensive, 'risk-averse' care approach.

Care organisations were seen to be facing increasingly high levels of dependency and frailty, particularly in mental capacity, on the part of their patients/residents. Combined with staffing and funding pressures, these changes were seen to have resulted in potentially 'higher-risk' care environments, both for staff and those for whom they cared. The constraints of the physical environment, particularly where not 'purpose built', were identified as a further challenge for care organisations. Organisations providing little recognition of, or support for, the work of their staff and operating a *'…perceived culture of blame'* (Tadd et al., 2011a: 6) were seen, potentially, less able to negotiate these risks effectively.

The evidence gathered on internal complaints systems is patchy, but indicates that they tended to focus on individual rather than institutional actions. For example, all (eight) care homes in one study had *'…workable policies and procedures'* (Killett et al., 2011: 89) in place to deal with 'one-off' complaints against individual members of staff, but no easy way for concerns about repeated breaches of safety and security arising from 'normalised' organisational practices to be identified, reported or addressed.

THE CARE ASPIRATION:

Residents/patients receive prompt and considerate attention, are accorded privacy in personal care and for personal affairs, with respect for rights, customs and beliefs and freedom from embarrassment, humiliation or shame,

provided by health and care staff who assess for dignity needs and display sensitivity when performing procedures, who are adequately trained and supported in the provision of dignified care, and are themselves treated respectfully and without discrimination or loss of dignity,

in organisations that ensure a respectful operational culture within an appropriate physical environment, and adequate systems and resources to monitor and ensure dignified care.

THE PANICOA STUDIES FOUND:

Residents/patients had a mixed experience in the extent to which they received dignified and respectful care. On the one hand, there were many examples of excellent practice and positive attitudes (see **Section 4**). These included care home residents being given a choice of food, appropriately modified utensils to eat it with, and alcohol with their meal, if so desired. In both care homes and hospitals, staff were generally found to be polite and pleasant and their use of first names or 'endearments' appeared acceptable to their patients/residents, even when the latter's preferences in this respect had not been ascertained.

On the other hand, studies also observed frequent use of disrespectful communication or *'elderspeak'* (Tadd et al., 2011a; 248) in both care homes and hospitals, such as referring to individuals by their bed numbers, or by the task involved (e.g. a 'double-hander'). Many examples were found, in particular, of negative attitudes towards older people on the part of clinical staff in hospitals, including addressing patients by the wrong name. Specific examples of undignified care were also identified, especially in toilet arrangements and/or lack of privacy (e.g. no locks on toilet doors). One of the worst examples witnessed was of hospital patients being told to soil incontinence pads, or to use bedpans/commodes, rather than being taken to the toilet. Minority ethnic care home residents in particular felt that they were not always treated with respect and they stressed the importance of culturally competent care to the maintenance of their dignity.

The balance of evidence suggests that most of the PANICOA research sites provided neither totally dignified nor totally undignified care and that, even on the same day in the same site, the extent to which patients/residents were treated with dignity and respect was *'…variable and unpredictable'* (Tadd et al., 2011a: 242). This inconsistency was seen to cause uncertainty and, at times, apprehension for older people and was not helped by lack of clarity about the expectations that patients/residents should have of the standards of their care.

Health and care staff were generally observed to be *'…clearly focused'* (Bowes et al., 2011: 63) on maintaining dignity and respect for residents/patients and were seen to find assaults on dignity troubling. Many reported that they were often prevented from providing fully dignified care, however, by pressures on time, resources and space. Environmental factors in particular, such as lack of single sex areas (especially toilets) and the proximity of beds, were seen to inhibit dignified care.

Variability was found in the extent to which staff themselves were treated with respect, including by patients or residents. There were cases of staff being publicly 'dressed down' or ignored by more senior colleagues in front of patients, for example. Some managers were seen to be hesitant to challenge poor practice, yet their lead on this was crucial. The role of hospital ward managers, in particular, was found to be pivotal in establishing an overall 'culture of respect' within the workplace.

Care organisations that took active steps to ensure their staff were valued and treated with respect were more likely to provide dignified and respectful care for their residents or patients. The influence of the wider workplace culture was clear. Dignity violations were 'often' found to result from *'...systemic and organisational factors'* (Tadd et al., 2011a: 7), such as the impact of risk management procedures, performance targets, skill barriers and/ or the sheer lack of time. Undignified or disrespectful care was not generally an isolated incident, nor restricted to an individual member of staff. If one person experienced a loss of dignity in a particular ward or care home, it was likely that many others did so too. The evidence of a widespread organisational attitude that acute wards were '...not the right place' for the care of older people was seen likely to represent a *'...significant barrier'* to the delivery of dignified care in hospitals (Tadd et al., 2011a: 247).

THE CARE ASPIRATION:

Residents/patients receive continuity of care and support, even when moving between providers/contexts, enabling relationships and trust to be built over time with carers and other key professionals and, wherever possible, enjoy continuity of place or 'social context',

provided by health and care staff who exchange relevant, accurate and timely information with other care professionals, who work effectively together to ensure coordination of services and who themselves experience continuity in, and efficient coordination of, their workloads,

in organisations that ensure sufficient resources and effective systems for internal information-sharing and work cooperatively with other providers across the health and care system to ensure integrated care and coordinated services.

THE PANICOA STUDIES FOUND:

Residents/patients in all institutional contexts valued continuity in, and effective coordination of, their care. Continuity of place and person, having a 'familiar face and environment', was seen to be an essential element of a positive care experience, particularly for those with dementia or complex conditions. For some minority ethnic residents, care continuity included the ongoing involvement of family carers. Hospital patients and their relatives stressed the particular importance of co-ordinated discharge planning. For care home residents, the continuity of their tenure in their current home was a central concern. In hospitals, the continuity of place was limited and consequential: the '…perpetual movement' of older people in and between hospital wards had caused them to feel that they did not '…matter much in the system' (Tadd et al., 2011a: 243).

Health and care staff were observed making positive efforts to enhance coordination and collaboration, including by involving administrative and 'housekeeping' staff in team-working, for example, or instituting 'patient rounds' rather than ward rounds to reduce patient movement. There was evidence that good teamwork was associated with staff feeling more 'empowered' to take decisions and work more flexibly.

Hospital staff saw the frequent movement of patients as an '…additional burden' (Tadd et al., 2011a: 243) and commonly perceived that this was being driven by targets on bed occupancy and/or waiting times. Clinical specialisation was also identified as a cause: bringing the patient to the specialist, rather than vice versa. In both care sectors, continuity and coordination of care were seen to be affected by high staff turnover and the resultant use of temporary or agency staff. In many contexts, care work was described as '…a series of tasks to be carried out' (Tadd et al., 2011b: 255) by staff who had no involvement in the care planning process. Little consistency or clarity was evident in the use of the 'named nurse' system.

Care organisations were seen to face challenges to continuity and collaboration due to a volatile policy and regulatory context. The almost continuous reorganisation of the health care sector, in particular, was considered a major impediment to the delivery of consistent person-centred care. Financial pressures were also judged to impact on continuity, especially in respect of staffing, and potentially to undermine effective collaboration within and between care

organisations. In the care home sector, these pressures could also make it difficult for providers to ensure 'continuity of place' for individual older people as they developed higher levels of dependency and more complex support needs.

The PANICOA evidence indicates the importance of internal 'connectedness' within care organisations, especially seamless lines of communication. Strong internal integration was essential to establishing internal consistency. This integration, however, was seen generally to be limited (in homes and hospitals) by hierarchical management systems that excluded frontline staff from involvement in care planning, and by the uneven or incomplete flow of information across the organisation.

THE CARE ASPIRATION:

Residents/patients have a key say in decisions about their care and support, exercising 'voice and choice' and feeling 'part of things' inside and outside the care setting, retaining their independence and exercising control over their lives for as long and as far as possible,

supported by health and care staff who are willing to work in partnership with individuals and (where appropriate) their families, by routinely seeking to involve them in decisions about the care they receive and actively working to support their independence; who are themselves encouraged and able to take an active part in decisions about the arrangement and delivery of care,

in organisations that ensure that older people have clear expectations about the standard of care they can expect, that provide the systems, resources and physical environment necessary to maximise independence of residents/patients, and that 'empower' their staff to work in flexible and proactive ways.

THE PANICOA STUDIES FOUND:

Residents/patients mostly welcomed the opportunity to be engaged in decisions about their care, although not all hospital patients wished to be involved in treatment decisions. There were examples

of care home residents adapting their care regimes in partnership with staff to suit their personal preferences and/or being able to personalise their physical environment. However, the opportunities to do so were variable and not generally extensive. While most homes allowed residents to bring in small items to personalise rooms, or as 'identifiers' on doors, the scope for greater control over the environment, such as rearranging furniture or having personal garden areas, was generally limited. In hospitals, the evidence suggests that, at times, little regard was given to the physical 'presence' of patients or their possessions: *'…wards and even bed spaces were very much the professionals' spaces'* (Tadd et al., 2011a: 248).

Health and care staff generally appeared aware of the importance of supporting independence, choice and control on the part of patients/residents and there was evidence of many active attempts to do so. These included a hospital initiative to inform patients in advance about what was going to happen to them that day. However, for NHS staff at least, this awareness was matched by a concern about achieving the right balance between empowering patients and *'…pushing responsibility on to them'* (O'Mahony et al., 2013: 89).

The PANICOA studies revealed a strong association between the empowerment of patients/residents and that of the staff caring for them. Active person-centred care was seen to be more likely to occur when frontline staff also felt that they were enabled to be *'…autonomous and responsible'* (Killett et al., 2013: 85) in their work. The evidence suggests however that the autonomy or engagement of frontline staff was not extensive. Health care assistants for example were seen to have only very limited involvement in decisions about the care of 'their' patients, adding to what was seen to be the *'…general sense of disempowerment'* (Schneider et al., 2010: 81) experienced by these staff.

Care organisations did not always appear to provide environments that maximised the independence of patients/residents. Hospital wards, in particular, were seen to constitute *'…disempowering spaces'* (Tadd et al., 2011a: 246) for older people, with lack of signage, discriminating colour and/or accessible information making it difficult for them to navigate their way around unassisted. Pressures on staff time were particularly critical and were seen likely to engender 'reactive' rather than 'proactive' care, markedly reducing the opportunity for older people to be meaningfully involved in decisions about their care.

Organisational systems also played a part in enhancing or diminishing independence and control. Flexibility in the *'…rhythms and routines'* (Tadd et al., 2011b) of care systems helped to maximise patient choice and the delivery of personalised care. In contrast, rigid working arrangements, including the use of standard care protocols, were seen to limit the ability of staff to respond effectively to, often complex, individual circumstances and needs.

The wider organisational 'attitude' to older people was identified as a crucial influence on the level of engagement and agency – and a particular issue in hospital settings. Geriatricians, for example, considered that 'disengagement' from older people was prevalent in the NHS, with the consequence that their perspectives were not routinely taken into consideration at an organisational level.

THE CARE ASPIRATION:

Residents/patients are able to maintain and develop meaningful relationships, in their personal life, with others in their care context and in the wider community,

supported by health and care staff who actively seek to provide relationship-centred care and who enjoy good working relations with colleagues, their team(s) and the organisation more widely,

in organisations that collaborate effectively with other organisations in the wider health and care sector and seek to develop and maintain good relationships with their local communities.

THE PANICOA STUDIES FOUND:

Residents/patients valued the development of relationships with staff, over and above the meeting of their care needs. This was particularly so for care home residents who sought *'...the warmth and degree of attention from staff that they would get from friends or family'* ("CPA", 2012a: 3). Relationships with other residents were also considered important and older people wanted to continue to enjoy their relationships with family and friends, as far as possible. Relatives and visitors in turn welcomed the opportunity to establish positive relationships with staff and, in care homes, to participate in the residential community.

In both care homes and hospitals, however, the extent to which patients and residents were able to enjoy positive relationships appeared variable. In some care homes there was evidence of *'...frequent friendship-like relationships'* (Killett et al., 2013: 63) based on reciprocity and mutual respect between staff and residents and, to a lesser extent, between staff and visitors. Particularly in care homes there were many examples of staff making visible efforts, via cultural and social events, for example, to strengthen relationships, both in the home and with the wider community. There were also examples, however, of staff appearing to prioritise their relationships with each other over those with their residents/patients. Despite many examples of good practice, care that failed to address *'...interaction, social life, spiritual life and family and community relationships'* was seen to be prevalent (Bowes et al., 2011: 69).

Health and care staff considered that delivering good care was easier when there were good relationships between all those involved. Care home staff in particular stressed the importance of developing *'...culturally competent'* (Bowes et al., 2011) relationships with minority ethnic residents. However, both health and care staff were concerned about having too little time to build these relationships. In hospitals, health care assistants (HCAs) were seen to play a central, but largely undervalued, role in this respect - effectively orchestrating the overall *'...emotional climate'* of wards (Schneider et al., 2010: 44). Despite their low status, HCAs felt they performed a socially important function and that their relationships with patients and relatives made their job rewarding.

However, relationships between patients/residents and their visitors or relatives could also be difficult for staff. For example, HCAs were seen to distance themselves at times from relatives, due to the *'...potential for misunderstanding and negative interactions'* (Schneider et al., 2010: 92). They were also seen to distance themselves emotionally from patients and relatives as a protective measure against

unpleasant tasks or emotional stress. Staff were appreciative of managers who supported them in difficult relationships or negative interactions with patients or relatives. However, the view that they were not supported, or listened to, by managers was a *'...common complaint'* (Tadd et al., 2011a: 238) from NHS staff.

Care organisations that actively facilitated internal 'connectedness' were seen to be more likely to develop a sense of a shared community, leading to more positive care experiences. Organisations lacking this connectedness tended to be viewed by their staff as a 'workplace', rather than as a place of residence or care, and by visitors as *'... places they attended, as opposed to places [where] they belonged'* (Killett et al., 2013: 65).

Some care homes appear to have made *'... impressive and genuine efforts'* (Tadd et al., 2011b: 113) to ensure that the building was the residents' home rather than just somewhere they were being cared for. In both care homes and hospitals, however, the opportunity to develop social relationships or to create a homely environment was at times seen to be hindered by the physical environment. Hospitals in particular tended to lack communal spaces for patients and visitors to meet, leaving some older people effectively isolated in side wards. This social isolation was compounded in some cases by extremely limited visiting hours.

THE CARE ASPIRATION:

Residents/patients have clear expectations about their care and receive accessible, relevant and timely information/advice to inform choice and underpin consent, including on any risks or cost involved, as well as full information about the staff and the organisation providing their care,

provided by health and care staff who use appropriate and accessible forms of communication with all those receiving care (and their relatives/carers), particularly those with special communication needs, and who have access to all organisational information relevant to that care,

in organisations that have effective internal communication strategies and systems for knowledge-exchange, ensuring the dissemination of appropriate and timely information to staff at all levels, and full transparency of operational goals and standards.

THE PANICOA STUDIES FOUND:

Residents/patients considered that 'good' communication was a central component of excellent care and that this included being listened to as well as being provided with enough of the right information to underpin choice. While individual hospital staff were reported to have gone to some lengths to communicate well with patients, many older people in acute wards considered that they lacked information about the staff and/or ward routines. This was seen to have impacted negatively on their sense of independence and control.

More positive examples of good communication approaches were found in care homes, particularly with residents with special needs due to language issues, or with particular conditions or impairments such as dementia. These included staff paying attention to body language, communicating through gesture or manner, and becoming skilled in alternative forms of communication.

Health and care staff also considered that good or effective communication, including active listening, was an essential component of excellent care. This was seen to be particularly important in relation to the information needed to underpin joint-working at 'handover' or 'transition' stages. Communication between nurses and healthcare assistants (HCAs) on patient information was generally found to be *'…well-supported and maintained'* (Schneider et al., 2010: 29), although there were relatively few opportunities for HCAs to engage in information-exchange with other members of multi-disciplinary teams, a situation potentially worsened by their lack of access to computers.

There is indication however that care home staff at times felt their work was hampered by a lack of relevant information about those for whom they were caring. Many health and care staff were seen to communicate well with patients with dementia, but others were keen to develop their skills in communicating with those with dementia and other complex needs. Staff in both hospitals and care homes considered that they had been excluded from important information about plans for organisational change, and few saw any prospects of this changing in the future.

Care organisations did not always appear to have effective systems for 'handling' important institutional information. This was despite communication evidently being seen as an organisational priority, necessary to ensure joined-up care, effective use of resources and a culture of

openness. A *'...recurring theme'* (Tadd et al., 2011a: 243) in the hospital studies, for example, was the perceived failure of the Trust to ensure that all staff understood policy directives and Trust guidelines.

Senior managers were typically seen to lack understanding of the pressures that frontline staff faced on a daily basis. Some organisations had established ways to address this issue, such as regular opportunities for staff feedback. However, much was seen to depend on whether the organisation had an active learning culture, willing to 'hear' as well as listen to concerns or issues raised. There was evidence, for example, that staff were less likely to engage with feedback systems if there was no indication of any action being taken as a result.

The significant recruitment of overseas staff was seen to have presented both care homes and hospitals with particular communication challenges. There was evidence that, in some care homes at least, the need for effective communication with and between staff for whom English was not the first language was being taken *'... very seriously'* (Tadd et al., 2011b: 134).

THE CARE ASPIRATION:

Residents/patients are able to retain a sense of individuality and identity, with their personal histories recognised and respected, and are supported to find enjoyment, stimulation and fulfilment in their everyday lives, feeling assured that their life matters and has a purpose. They are enabled, wherever possible, to live by the values and beliefs that provide their lives with meaning,

supported by health and care staff whose particular contribution and value to the organisations in which they work is acknowledged, and who are enabled to identify and achieve their personal development goals,

in organisations that have a clear and demonstrable understanding of their core purpose, values and goals, as well as of their role in the wider 'institutional care community'.

THE PANICOA STUDIES FOUND:

Residents/patients appeared to vary considerably in the extent to which they were supported to retain a sense of identity and purpose - in or outside their place of care. Many examples were found in care homes of older people, including those with advanced dementia, actively and purposefully engaged with the world around them and *'…experiencing joy'* (Brooker et al., 2011: 96). There were *'…*

shining examples' (Bowes et al., 2011: 66) of efforts by staff to support the cultural identity of minority ethnic residents. In hospitals too, there were examples of purposeful activity being used to reduce restlessness and agitation in patients with cognitive disturbance, in a range of different types of wards.

However, meeting the physical needs of older people emerged as the primary concern of hard-pressed staff; much less attention appears to have been paid to identifying or responding to their emotional, cultural or spiritual needs. In both hospitals and care homes there was evidence of a widespread lack of stimulating activities for older people. One study, for example, highlights the *'… boredom and dejection'* (Tadd et al., 2011a: 8) seen to have resulted from the lack of communal space or social activities in hospitals.

Health and care staff also varied in the extent to which they appeared willing, or able, to connect to the *'…individual behind the care'* (Tadd et al., 2011a). Some seemed very knowledgeable about the life histories of their residents/patients, but others much less so. Where staff were knowledgeable about individuals' backgrounds, this was seen likely to increase older people's level of social interaction and their enjoyment of the environment.

Frontline staff in care homes generally reported high levels of personal accomplishment and a *'…strong sense of mastery'* (Tadd et al., 2011b: 83), although this was variable. A *'…noteworthy minority'* (ibid.) however indicated a sense of depersonalisation, associated with lower levels of skill attainment. Overall, greater confidence, as well as competence, was seen to result from training, and staff reported that participation in staff development increased their sense of being valued.

Nursing staff generally expressed a sense of achievement and job satisfaction. This was less typically the case for health care assistants, however, some of whom saw themselves as *'…devalued members*

of the hierarchy' (Schneider et al., 2010: 88) whose role was *'…seldom affirmed'* by the rest of the team. Care staff from minority ethnic backgrounds were seen to experience particular challenges to their self-esteem, due to the stigmatisation of care work in their communities and/ or the tendency of some minority ethnic residents to treat them as servants (Bowes et al., 2011).

Care organisations had a central influence over the extent to which their staff enjoyed a sense of purpose and achievement. Opportunities for training and development, in particular, were seen to be central to confidence and self-esteem, especially for staff on the 'frontline', as were fair and transparent systems for recognition and reward. There is evidence that a more generalised organisational concern with staff well-being, providing practical and psychological support on work- and non-work-related issues, was *'…a striking feature'* (Killett et al., 2013: 88) of those care homes that achieved positive care experiences for residents.

The degree of personal engagement with older people and their lives appeared also to be institutionally, rather than individually, determined. This was particularly so in the care home context, where one study found that, if there was *'…a lack of empathetic connection'* (Brooker et al., 2011: 96) with one resident, this was likely to be the experience for all residents in that home.

SECTION 4: THE PANICOA FINDINGS ON A 'RESPECT AND PROTECT' CARE CULTURE

THE RELEVANCE OF CULTURE

This Section considers the evidence from the PANICOA studies on the impact of an organisation's wider culture or 'behaviour' on its ability to ensure a consistent 'respect and protect' care service. A useful definition of 'culture' is provided by Schein:

The pattern of shared basic assumptions – invented, discovered or developed by a given group as it learns to cope with its problems of external adaptation and internal integration – that has worked well enough... to be taught to new members as the correct way to perceive, think and feel in relation to those problems (Schein, 1985, quoted in O'Mahony et al., 2013: 29).

The PANICOA studies found that, in the main, care staff were working hard, often in difficult circumstances, to provide good levels of care but that, despite this, various forms of mistreatment, including neglect, loss of dignity and (indirectly) abuse, were observed or reported. A common theme across the studies was the central influence of the wider organisational culture on the quality of the care provided by individual staff:

We found examples of excellent care, with inspiring and sensitive approaches to individual residents and we also found homes working hard to provide good care. But we also found examples of impoverished care where individual residents experienced little engagement or activity or received insensitive help. Differences in the organisational culture were associated with these different experiences of care (Killett et al., 2013: 1).

Examining the impact of organisational culture or 'behaviour' helps us answer the key question of why 'good', well-meaning people (staff, residents/patients or relatives and visitors) can end up doing harmful or neglectful things and how, less commonly, 'ill-intentioned' or thoughtless people can be prevented from causing harm, neglect or loss of dignity to those for whom they care.

ATTRIBUTES OF A STRONG 'RESPECT AND PROTECT' CARE CULTURE

While the PANICOA studies do not suggest that there is a single 'right' culture, they indicate that certain kinds of organisational behaviour or characteristics are likely to predispose to positive care experiences. These key attributes are set out below.

▶ 'person-centredness' is a core value

All studies were agreed that a 'person-centred' approach, where the needs of the resident or patient are 'paramount' to the organisation, was an essential element, if not prerequisite, of a positive care culture. Positive care experiences for older people were more likely to occur where there was strong organisational understanding of their specific needs and a clear strategy for their care. This was particularly important in organisations, such as hospital acute wards, that cater for general populations.

Person-centredness is not just about responding to an individual's care needs and circumstances, but about involving them directly in decisions about that care. Organisations that embedded the activity and engagement of patients/residents in their work were more likely to deliver positive, person-centred care, even with shortages of staff or resources. Engaging relatives and visitors in decisions about the wider care context, moreover, could enrich resources and contribute to more positive *'...organisational dynamics'* (Killett et al., 2011).

▶ core values are clear and shared

Development of a person-centred approach was more likely when there was a clear understanding of its 'core value', shared across the organisation. The existence of a *'unified organisational purpose'* (Killett et al., 2013) was associated with more positive care experiences. In contrast, unclear communication of organisational values, or the existence of competing values between different parts of the organisation (for example, between professional and managerial lines of accountability), were factors seen potentially to undermine a positive care culture.

It is important that the principles of a person-centred approach are clearly reflected in organisational priorities and actions, for example in the recruitment, appraisal and reward of staff. A more positive care experience was likely when these principles were 'visibly' demonstrated by staff at all levels of the organisation:

> *"The most important part of my job is making sure that everybody in the home gets proper person-centred care, and that they feel they're wanted and valued and that they're well looked after and that it's their home and that the staff do their best to facilitate that…And that's what I try to filter down to the staff that are on my team"* (Team Leader, care home in Killett et al., 2013: 49).

External factors, such as financial constraints, regulatory requirements or policy change were seen to challenge the achievement and maintenance of person-centred care. Different external 'drivers', from different sources, could lead to competing operational priorities and, at worst, tension between the needs of the organisation and those it cared for. As one geriatrician put it, a case of *"…managing the hospital, not managing the medical condition of patients"* (O'Mahony et al., 2013: 223). The changing regulatory context was seen as a particular challenge. In both care homes and hospitals there

was *'a strong sense'* that organisations were facing a growing volume of requirements and that this was tending to encourage task-based rather than person-centred care (Tadd, 2011a and b).

However, while all care organisations were facing these pressures to some degree, they differed in the way in which they responded to them. Some struggled to maintain consistency of quality while others appeared to be more resilient *'…buffered by the capacity to adapt'* (Killett et al., 2011: 30). The difference was the strength of the organisation's 'capability for change'.

▶ the 'capability for change' is strong

Change is inevitable and the inability of organisations to value change, or recognise its necessity, could adversely affect the quality of the care culture. Effective internal 'mediation' of externally-driven change was seen to be key. Where managers could find ways to cushion its impact, or to translate it into better practice, this resulted in a more positive care experience. For example, those who were able to absorb external regulatory requirements as a framework for good care, rather than as a driver of activity, appeared able to adapt more successfully:

> *'…in [care home]…the regulation and regulatory aspects were absent from the rationale, discourse and practice of daily life in the home: CQC does not drive this home, [regulatory action] is something they do because of the home, rather than their reason for running the home'* (researcher observation in Killett et al., 2013: 70).

Organisations need strength to resist external priorities or values that could undermine a person-centred approach. Doing so requires an ability to anticipate the potential impact of external pressures on the quality of care and to take active steps to ensure that the welfare of residents and patients is at the centre of the organisational response:

...staff, (sometimes with resident input), were shown to have developed collective ways of responding to pressures in the delivery of care. For instance we found examples where care staff had involved medical staff in helping them influence contracted out catering services to provide the food a resident with dementia liked. This was talked about as 'getting the doctor to prescribe a resident sausages' (Killett et al., 2011: 7).

A range of factors was seen to contribute to enhancing the organisation's capacity to mediate change effectively – most centrally, the quality of its leadership at both corporate and ward/home level.

▶ leadership is strong and visible

Leadership is more than just good management; centrally it involves the ability to influence and inspire others across an organisation: *'Management is doing things right. Leadership is doing the right things'* (Drucker, 2009). Successfully embedding the values of a person-centred approach was seen to require 'proactive' leadership, and one that has a visible 'presence' at all levels in the organisation. Positive care experiences were found to be associated with senior staff leading by example through their involvement in the day-to-day running of the home or ward:

"If you look at wards that are good, they are usually well led, all the things that are supposed to happen, happen because somebody shows leadership to ensure those things do happen and things that shouldn't happen, don't happen" (Geriatrician in O'Mahony et al., 2013: 166).

Positive care experiences were also associated with a 'dispersed leadership' approach that encourages and supports staff across the organisation to take responsibility - within clearly defined boundaries and expectations. Having greater autonomy and control over their work was found likely to increase the commitment of staff to the values of

the organisation and their creativity in pursuing those values in practice:

"You know, when we first had animals I had terrible trouble upstairs with the Committee because they said: 'We don't like animals, why have you got them in?' So we talked to them about it and then wrote it in the Newsletter, the benefit that it gave to residents...and just kept talking about it and saying: 'But it's not going away, whether you think it's good or not, we know it is' and eventually they came in" (Geriatrician in Killett et al., 2013: 99).

The ability to inspire staff to 'care well' is a key element of good leadership. Strong leadership is also needed to ensure that the core values and purpose of the organisation are embedded in all areas of its activity, including in the management of its key resource: its "Human capital".

▶ staff are valued and supported

Ensuring sufficient capacity and capability is a central challenge for care organisations. Inadequate staffing levels, an inappropriate 'mix' of skills, large workloads and high levels of staff 'turnover', sickness or absenteeism, were all found potentially to undermine continuity and quality of care. The ability of organisations to manage staffing requirements proactively in the face of budgetary pressures and fluctuating levels of resident/patient need was a major determinant of a positive and adaptive care culture.

The organisation's ability to value and support its staff is also central: if staff are to create an *'...enriched and empowering environment'* for those for whom they care, they need to experience this themselves (O'Mahony et al., 2013). Overly bureaucratic or 'instructive' management styles, with rigid routines or entrenched processes, were less likely to be associated with good quality care. A culture of trust and openness where staff feel able to make suggestions for change, or express concerns, was strongly associated with a more positive care environment.

Supportive and responsive management that 'empowers' staff to adapt established systems to meet the particular needs of residents/patients was also a postive factor:

A resident with complex needs required almost constant care as [s/he] neared the end of life. This increased demand on the care home staff. In response...the usual routine of providing the residents their evening meal in the dining room was changed. Instead a decision was taken by the care worker in charge to 'do a lap tea' that afternoon, where residents were served sandwiches and drinks from a trolley in the sitting room or in their bedrooms. All the staff and also the residents... appeared to understand this change as a reasonable response to a situation of particular demand (Killett et al., 2011: 32).

The motivation and morale of staff are essential to good quality care: *"Most staff in the NHS don't come to work to neglect anybody; most common forms of neglect are probably due to thoughtlessness...or sometimes it is purely the pressure of work and demotivation"* (Geriatrician in O'Mahony et al., 2013: 208). Job satisfaction and a sense of achievement help to maintain morale. An enabling and responsive management approach is important; one that actively and visibly values and supports staff at all levels. This requires formal systems for staff development/appraisal that are transparent and fair, and provide the opportunity for reflection on practice, as well as the development of more informal ways to provide feedback from peers and residents/patients:

"The staff and patients can vote for people...and there is something like ten categories, so it allows you to reward the people who perhaps don't come to the fore on a general basis. The other thing we do is celebrate the people who do best. We hold them up as, you know, good examples" (Director of Nursing in O'Mahony et al., 2013: 210).

In addition to its 'human resources', the physical (non-staff) resource available to a care organisation, and the way this is managed, will also have a strong influence on the quality of care provided.

▶ the physical resource is effectively managed

While the available financial resource is important to the work of any organisation, the PANICOA studies found that a secure funding base was a necessary, but not sufficient, condition for a positive care culture (Killett et al., 2103: 131). Other factors had an important part to play. The management of the physical environment of the home/ward, for example, was found to have a strong influence on the quality of care provided. The studies revealed a *'...complex relationship between design, space, and practices within that space'* (Killett et al., 2013). The layout of the care environment, in particular, could operate as a barrier or facilitator to the delivery of person-centred care.

Positive care experiences were more likely to result when decisions about the use of space were driven by a shared commitment to person-centred care. Organisations that regularly took steps to reflect on the use of space and environment were found more likely to provide a positive care experience, especially when this was undertaken with the active involvement of residents/patients or relatives/visitors.

"We have no dining rooms in this hospital for patients and we've actually commandeered waiting rooms to turn them back into areas to eat and what's been amazing is the phenomenal difference in patients eating habits...because they're eating in company ...if they eat alone their uptake of diet is less whereas we've seen them chatting away and eat(ing) more because they're sitting at a table and they're not noticing what they're eating... for most elderly patients, actually, the food isn't what that time is about, it's about the sociability of it all" (Director of Nursing in O'Mahony et al., 2013: 217).

Effective management of the organisation's environment will need a 'joined-up' use of both its human and non-staff resources. The development of an internal *'sense of connectedness'* across the care workplace (Killett et al., 2013: 6) was found to have a strong positive impact on the quality of the care experience.

▶ the organisation is connected

Developing 'a sense of connectedness' between staff and residents/patients, especially via strong team-working, was found likely to improve the continuity and consistency of care provided. It could also lead to the more efficient use of resources by avoiding duplication or fragmentation of service. It was not only the integration of staff that was important, however. The involvement of residents/patients as integrated team members or 'partners in care' was seen likely to lead to more positive care outcomes:

"We'll encourage relatives to come in if they want to, because it will help them feed their patient and it could be a nicer experience then, maybe not as rushed as if the nurses were doing it. The relatives feel that they're still having input and it's not them and us, it's kind of we're all working together to try and get the patients home" (Ward Sister in O'Mahony et al., 2013: 189).

External connectedness - with other organisations within the wider health and care community - was also seen to be important. The isolation of an organisation was likely to have a negative impact on the quality of care it provided. In contrast, working effectively with 'partner' organisations, across *'...low boundary walls'* (O'Mahony et al., 2013), was associated with a more positive care experience. Seamless information-exchange was found to underpin connectedness, both internally and externally, including, importantly, between the organisation and those in its care:

"We're about to go live [with a new project] where patients will be given access … they will be able to view openly all of their letters. So all of their communication that consultants have with the GPs and with other Trusts about the patient they will be able to view, read and access"(Executive Director in O'Mahony et al., 2013: 188).

▶ there is an active learning culture

A learning organisation that is prepared to do new things and learn from the past is likely to provide a resilient and adaptive care environment. Entrenched 'ways of doing things' and resistance to change were seen potentially to impact negatively on the provision of care. An organisation that is able to identify and respond quickly to risks or problems can help minimise their impact at both the institutional level and the level of individual care. This is not just about learning from mistakes, or 'near misses', but being in a position to anticipate (and avoid) potential risks:
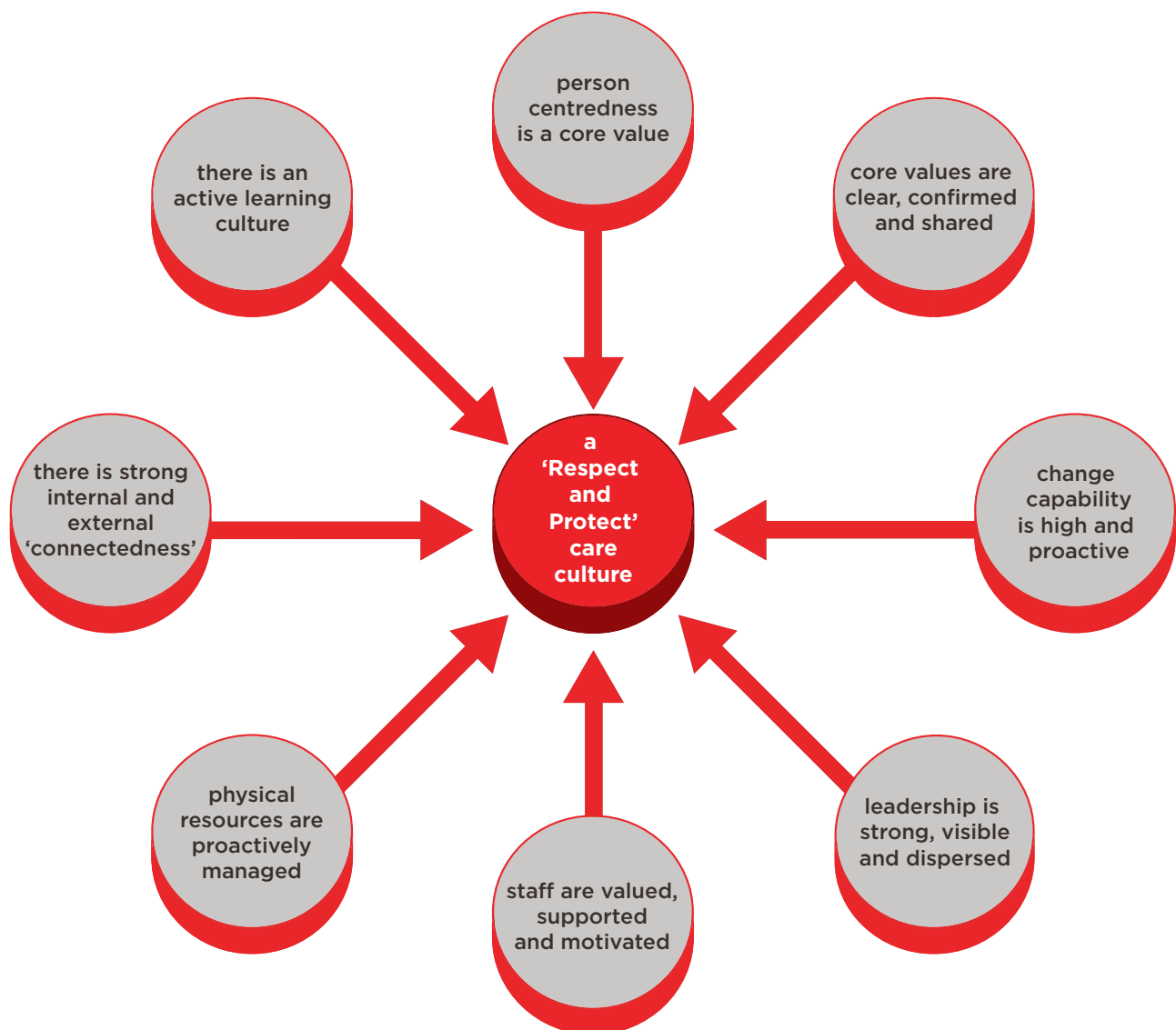
"…we had a significant number of falls with harm… and one of the things we've done is got the charities to fund slippers for patients, proper slippers, not those awful foam ones that you get, the disposable ones… for the elderly a slipper with an ankle support, with solid bottoms which means they are not walking on bare feet or in those anti-embolic stockings actually onto our slippery floors. So that … has meant we've reduced our falls with harm by a huge amount in the last two years" (Director of Nursing in O'Mahony et al., 2013: 180).

The collection of good quality data is central to the organisational learning process and to engaging staff in ongoing quality control and improvement.

Assessment systems need to reflect and support the stated core values of the organisation. This needs investment, however, of time and resource and can involve risks, such as creating a 'tick box' culture that depersonalises care. The collection of data needs to be linked to staff feedback, to inform and improve their work or to demonstrate a timely response to an identified problem. A sense that data are being collected routinely, to no visible end, can be frustrating or demoralising for staff.

Quality is 'complex and multi-faceted', moreover, and some key aspects of organisational performance, such as staff motivation, can be difficult to capture: *"...there's no dashboard indicator for passionate nursing staff"* (staff nurse in O'Mahony et al., 2013: 2591). To underpin person-centred care effectively, data collection needs to cover all the 'domains of quality', both process and outcome, and involve measures that are 'holistic' and patient-centred: '...assessment FOR quality, rather than OF quality' (ibid.).

person centredness is a core value

there is an active learning culture

core values are clear, confirmed and shared

there is strong internal and external 'connectedness'

a 'Respect and Protect' care culture

change capability is high and proactive

physical resources are proactively managed

staff are valued, supported and motivated

leadership is strong, visible and dispersed

CULTURE IS COMPLEX AND DYNAMIC

The organisational factors that were seen to predispose to a positive *'respect and protect'* care culture are summarised visually in **Fig. 3** (left). While the presence of all the identified organisational attributes will not prevent poor care experiences, it will mean that negative experiences are likely to be less common and more likely to be counteracted by other more positive organisational influences. Contrariwise, while a negative care culture will not necessarily preclude good individual care, it will mean that positive care experiences tend to occur 'against the grain' (reliant on individual initiative or determination) and are less likely to be reinforced by other aspects of organisational behaviour.

There may not be a single dominant culture in any one organisation, however. The PANICOA studies indicate that multiple, often contradictory, subcultures are able to coexist: one of 'trust and openness' with another of 'subversion and secrecy', for example, or 'hierarchical' systems with those of more *'open governance'* (O'Mahony et al., 2013). It is the interaction of these different sub-cultures, the *'…organisational dynamics'*, (Killett et al., 2011) that will have a determining impact on the quality of the overall care culture.

Importantly, the PANICOA studies indicate that an organisation's culture is not fixed in time, but constantly evolving: *'…locally and contextually created, shifting and delicate'* (Killett et al, 2013: 2). Even in 'good' care organisations, a combination of internal or external factors can interact in ways that shift the cultural *'balance'* between good or unstable/inconsistent care (Killett et al., 2011). Finding ways to identify the signs or 'markers' of organisational 'ill-health' or weakness, ideally at an early stage, seems essential. The PANICOA research also shows that organisations that face the same pressures can experience and respond to them in very different ways. A further challenge for both care and research communities, therefore, is to understand better the characteristics of an organisation that serve to strengthen or weaken its resilience to 'environmental shocks'. This key issue is returned to in the **Discussion** section of this Report.

SECTION 5: THE PANICOA NARRATIVES

The PANICOA studies set out to examine the causes and consequences of the mistreatment of older people from a range of perspectives. These included, centrally, the experience of older people themselves as patients or residents, and their relatives/friends, but also the views and experiences of the staff and the perspective of the care organisations involved. Drawing these 'voices' together from across the studies has revealed a number of different 'ideal-typical' sets of experiences, or 'Narratives'.

These Narratives are "Indicative" only; the PANICOA studies set out to illuminate, rather than quantify, the different experiences and perspectives involved. Given the largely exploratory nature of the research designs, it goes without saying that they make no claim to statistical generalisability. Combining the findings of the individual studies, however, produces some consistently strong themes. The strength of this thematic correspondence suggests that the experiences reflected in the Narratives are likely to be typical of those in care homes and hospitals more widely.

NARRATIVE 1: THE RESIDENT OR PATIENT

Residents and patients generally experience a level of direct care that is good, at times excellent, in both hospitals and care homes. The risk of physical assault is low, although there may be a risk from other residents/patients if challenging behaviour is not responded to effectively. The risk of physical harm, or neglect, from care that is neither timely nor sufficient, is greater, however, and the lack of privacy and dignity in personal care, especially around using the toilet, is a reliably negative experience. Disrespectful treatment is common in hospitals, and patronising or 'infantilising' communication ('elderspeak') is prevalent in both care

contexts. The most notable feature of the patient/resident experience, however, is the variability and unpredictability of care, even in a single site on a single day, leading to uncertainty and apprehension for many.

The care experience is frequently impaired by physical environments that are not purpose-built for highly dependent older people, particularly those with dementia and other cognitive difficulties. The layout of wards/homes is likely to lack clear signage or discriminating colour, making it difficult for older people to navigate their surroundings. This can undermine both the sense and the reality of independence. Hospitals in particular can be experienced as 'disempowering' spaces for older people, with intimidating-looking machinery, frequent changes of wards and few, if any, social areas to meet with visitors or other patients. Scant respect is typically accorded to the personal space or 'presence' of older people in hospital wards. There is little stimulating activity for older people in hospitals or care homes, and a general sense of boredom and dejection is evident in both care contexts.

On the whole, residents and patients are likely to find staff making positive efforts to build relationships with them, particularly in care homes. The 'person-centredness' of their care however can be sidelined as their physical needs are prioritised by hard-pressed staff. Communication by staff tends to be clear and particular efforts are made with those who have special communication needs. But lack of information about staff or ward routines can be a problem for patients in hospitals. Overall, patients and residents have the opportunity to be actively involved in decisions about their care, but the degree of control that they can exercise over their care environment will be limited.

Perhaps as a result of such experiences, patients and residents tend to have relatively low expectations of their care and, particularly in hospitals, are unwilling to be seen to be asking too much of staff. Workable procedures for raising complaints will normally be in place but, in both homes and hospitals, these will tend to focus on individual, rather than institutional, mistreatment. The few who do raise concerns are likely to meet with defensive responses, and there is unlikely to be consistent support for those with confusion or limited capacity. It is not easy, in either care setting, for patients or residents to report repeated breaches of safety and security arising from 'normalised' organisational practices that could be considered cumulatively neglectful. Yet this area of organisational mistreatment, rather than that deriving from individual action or behaviour, is typically the more prominent feature of the care experience.

NARRATIVE 2: THE CARE STAFF

Professional and frontline staff are typically hardworking and committed to delivering care that respects the dignity of older people and supports their independence and self-determination. They recognise the importance of effective communication with older people, particularly for those with special communication needs, and of providing adequate information to underpin involvement and choice. NHS staff, however, may temper this commitment to involvement with a concern not to place too much responsibility onto patients. While staff generally value good relationships with older people and their supporters, they can at times find it necessary to distance themselves from a patient or resident in order to accomplish emotionally difficult tasks.

Staff are frequently frustrated in meeting care objectives, however, by constraints of time, resources and the physical environment. Pressures of time, in particular, can result in 'reactive' care that reduces the opportunity for the informed participation of the older person. High levels of staff turnover or absenteeism, and the heavy dependence on temporary staff, undermine the continuity and coordination of care and result in a more fragmented care experience. Typically, much basic 'hands-on' care is undertaken as a series of unrelated 'tasks' performed by less experienced/unqualified staff with little or no involvement in the care planning process. Frontline staff are likely to feel they lack relevant information about those for whom they care and, especially in hospitals, see little opportunity to share their knowledge or concerns about 'their' patient/resident with more senior colleagues.

Care staff are themselves frequently at risk of verbal or physical aggression, with minority ethnic staff facing additional problems of individual or institutional racism. The experience of work-related stress and emotional 'burn-out' due to workload pressures is not uncommon and personal strategies to manage stress can lead to staff disengagement from patients/residents or to a more defensive, risk-averse, approach. The ability of staff to respond effectively to the changing circumstances and needs of older people is frequently frustrated by inflexible organisational routines and systems.

The overall level of job satisfaction is low, although higher for nurses than for care assistants in hospitals or homes. Hospital health care assistants, in particular, feel their role is seldom affirmed by the wider care team and experience a general sense of 'disempowerment'. Staff are generally keen to develop their skills and capabilities but the opportunities to do so are limited and often considered unsatisfactory. In both care homes and hospitals staff feel excluded from key information, especially about organisational change, and typically feel that managers lack understanding of the daily pressures they face and are not fully supportive – particularly when things go wrong.

NARRATIVE 3: THE CARE ORGANISATION

Growing levels of dependency in their elderly populations present health and care providers with a major challenge. The greater number of older people living longer with dementia or other cognitive impairments and/or multiple conditions is necessitating the provision of 'higher-risk' care environments. The structure and organisation of hospitals, with their focus on medical specialties, is generally failing to keep up with the changing demographics of older people, who are now undeniably their main users. Providing continuity of residence for older people as they become increasingly frail and dependent is a growing challenge for care home providers.

Financial constraints across the health and care sector are putting pressure on resources, especially for care homes with large numbers of publicly funded residents. Difficulty in recruiting and retaining appropriate staff is common. This is particularly so in care homes, but constraints on ward budgets are increasingly resulting in 'untenable' staffing levels. High staff turnover and increased use of temporary or agency staff bring additional workload management pressures. The recruitment of staff for whom English is not the first language brings additional communication challenges in care homes, for residents and visitors as well as staff teams.

Providers differ widely in their ability to negotiate this difficult context effectively. Some display a strong capability for change, with an ability to 'buffer' the impact of external pressures and anticipate or mediate change in the interests of patients/residents. In many others, this 'change capability' is constrained by entrenched systems or inflexible ways of working. In the NHS, in particular, a focus on practice audits and risk-management strategies is encouraging more defensive and 'risk-averse' organisational cultures and reducing the potential for professional judgement or individual initiative.

The quality of leadership, across both sectors, is of uneven strength and visibility, with a tendency to centralisation. Hierarchical organisational structures are common, with little downward dispersal of authority and limited established team-working between senior and frontline staff. The autonomy of care home managers is often highly limited. Internal communication is not an evident strength, with many organisations, especially hospitals, lacking effective or routine systems for transmitting essential information to staff at all levels.

Organisations vary in the extent to which they have developed a culture of 'activity and involvement' - associated strongly with the delivery of safe and respectful care. Those that make efforts to engage relatives, visitors and others in their work find this has a positive effect on the overall organisational 'dynamic'. This effort is more likely in care homes than hospitals, however, where a widespread organisational 'disengagement' from older people is evident. There is also variation in the organisational 'attitude' to older people. This is critical in establishing the overall 'emotional environment' of the care setting and is strongly associated with a more positive patient/resident experience. Again, this is generally less positive in the hospitals where there is a prevalent view that acute wards are not the right place for the care of older people.

NARRATIVE 4: THE WIDER CARE COMMUNITY

There is a fourth Narrative discernable in the PANICOA evidence, although less clearly delineated than those above. This concerns the relationships between the different key bodies, public and private, operating in the wider institutional care context. This Narrative is largely 'provider-centric': not all participants in the wider community were in the research focus. There was no investigation, for example, of the perspectives of commissioners, regulators, and safeguarding bodies whose work is central to the quality of care.

And the important role of charities, local communities, or of the public more widely, in prevention of mistreatment was not under study.

Nevertheless, the research provides an emergent Narrative around some of the key features of the wider "Community of purpose" involved in the institutional care and protection of older people. It suggests there are clear strengths across both health and care provider sectors, not least in terms of a commitment to collaboration and an evident ability to work well together, often in challenging circumstances. The sharing of these strengths is not so evident, however, with only limited cross-fertilisation of good practice, particularly on safeguarding, between organisations working in different sectors of the care community.

There appears to be only limited connectivity in the work of key 'partner' organisations. The distinctive roles and responsibilities of different regulators, commissioners and safeguarding bodies, for example, are not always mutually clear and there is evidence of a lack of 'read-across' in the organisational systems or practices of these diverse bodies. Collaboration on information collection and exchange is a notable area of weakness, especially in the sharing of complaints or concerns about mistreatment between the different regulators. Data on safeguarding are piecemeal and their collection is unsystematic (centrally or locally) - requiring collation from disparate sources. There is no single national data set on the mistreatment of vulnerable adults in institutional care and the area remains bedevilled by *'... endemic problems of confusion of terminology and definitions'* (Manthorpe et al., 2011: 65) - see **Annexe 3E**.

The issue of funding emerges as a key area of potential 'dissonance' across the community. Current arrangements appear complex and uneven with clear 'disconnects' in the nature of their interrelation. The variability of assessment thresholds and fee structures, for example,

is a major concern for both 'providers' and 'customers' in the care home sector, as is continued uncertainly about the level of the state contribution to meeting long-term costs. Commissioners are not seen fully by providers to acknowledge the implications of caring for more dependent populations, and/or are not able fully to meet the costs of so doing. Inconsistency in the requirements and opportunities for staff training, both within and between health and care sectors, is a persistent source of underlying tension.

The overall 'emotional climate' around the institutional care of older people appears to be generally cool, not least due to the high public profile given to examples of poor performance or 'adverse events'. Care home providers tend to feel that their work is not well understood or fairly regarded by government, regulators or the public more widely. Regulation, which should be of clear benefit to good providers and supportive of those working to improve, is typically viewed (at least in England and Wales) as complex, inconsistent and variable, making it difficult for hard-pressed organisations to keep 'ahead of the curve' and plan effectively for the future. Safeguarding processes are not considered proportionate to the level of actual risk and, as with those of the regulators, are seen to focus more on apportioning blame than on providing support and assisting development. Together, these (and other) factors militate against the development of a 'culture of connectivity' across the wider institutional care community.

The individual PANICOA studies produced many messages and recommendations relevant to the themes and issues set out above. These have been combined into two broad sets of actions or **Templates for Good Practice**, designed to support to the development or maintenance of a 'respect and protect' care service and care culture. It is recognised that, in many cases, the messages will confirm already established, or developing, areas of good practice. Where this is not the case, they are offered as a resource to support improvement.

TEMPLATE FOR A 'RESPECT AND PROTECT' CARE SERVICE

IN CARE HOMES AND HOSPITALS

Frontline care staff:

• take account of the older person's feelings and concerns in delivering intimate care by maximising privacy (especially in using the toilet) and by being aware of the presence and impact of ageism, and other inappropriate attitudes, in these and all other care tasks.

Care home/ward managers:

• routinely monitor the housekeeping workloads of frontline staff with the aim of minimising absence due to work-related injury or avoidable stress;

• create an active learning environment by giving frontline staff regular 'protected time' to develop relationships with those for whom they care, to reflect on best practice in safe and respectful care, and to review inappropriate practice on the part of themselves or others;

• be visibly engaged with the patient/resident and frontline staff experience and be willing to challenge inappropriate or poor practice at all levels of the organisation; take necessary action to prevent its recurrence;

• give consideration to the challenges faced by multicultural staff groups who may be subject to racism or discrimination; recognise, and reward appropriately, the additional skills required for work in multicultural contexts;

• recognise that minority ethnic residents/patients and their families/friends may face particular difficulties in raising concerns/complaints, develop a 'proactive' approach to enable them to feel able to raise issues without fear of reprisal or repercussion;

• ensure that privacy signs are always used when personal care is being undertaken.

Senior managers/owners:

• provide an explicit and accessible statement to new residents/patients outlining the specific standards that they can expect of their care, and establish accessible mechanisms for them (or their relatives/friends) to feed back to staff/managers on how far these expectations are being met;

• on admission/arrival, ensure that a relevant member of staff is identified to develop the required personal care plan, and that this is drawn up with the active involvement of patients/residents (and, where relevant, relatives/friends) and frontline staff;

• appoint a lead professional/key worker to have responsibility for the overall continuity and coordination of an individual's care; this includes ensuring that the personal care plan is regularly reviewed and updated to meet changing needs;

• ensure that patient/resident feedback, along with other relevant organisational information, is cascaded down to staff at all levels, including those working on the frontline and in support roles;

• regularly review the operation of organisational systems and practices to identify and adjust any that serve to discourage a 'person-centred' approach to care-giving;

- ensure that all areas have adequate lighting and appropriate safety controls (e.g. on water temperatures) and that staff know how/when to use them;
- provide sex-specific washing and toilet areas wherever possible;
- actively promote take-up across the care home sector of the "Keys for Care" product from the Relatives and Residents Association.

Commissioners/regulators:

- ensure contracted care organisations commit adequate resources to provide a sufficient number of appropriately trained staff on site at all times, and have a robust workforce strategy to minimise, or manage the impact of, the use of temporary or 'agency' staff;
- monitor staff levels in hospitals and care homes as part of the inspection process.

IN HOSPITALS

Senior/ward managers:

- establish ways to integrate the knowledge held by health care assistants on individual patients routinely into the care process, for example by including them in ward rounds and/or team discussions;
- encourage clinicians to engage in shared care and joint responsibility for patients whose condition cuts across clinical specialities; require consultant/teams to undertake 'patient rounds', rather than ward rounds, in order to reduce the need to move patients between wards;

- ensure that all older people in acute NHS care settings with complex conditions are seen by an old-age specialist as soon as possible to advise on care management and to liaise with specialist services, especially for people with dementia;
- provide social areas on acute wards in recognition of their value in promoting recovery and/or preventing deterioration.

IN CARE HOMES

Senior managers/owners:

- in the absence of pre-entry training, ensure that all new care workers - including support staff - receive formal induction before allowing them to work unsupervised; at a minimum this should cover respectful communication, safe and dignified person-centred care, dealing with challenging behaviour and identifying and managing risk.

Care home managers/staff:

- instigate a variety of ways to support social interaction and shared activity in the care home, including between residents/relatives/friends/visitors and staff; proactively develop links with the local community, schools and charities to increase awareness of the care home and its residents, and to encourage greater interaction.

TEMPLATE FOR A 'RESPECT AND PROTECT' CARE CULTURE

IN CARE HOMES AND HOSPITALS

Senior managers/owners:

- deliver a strong and clear message to staff at all levels about 'zero tolerance' of abusive or neglectful care and visibly reflect this core value in their own work;

- establish processes to assess the values and assumptions of care staff to ensure alignment with the organisation's core values; use this assessment in performance review to help staff reflect formally on the way they work;

- develop mechanisms to assess regularly the impact of the care environment on resident/patient safety and privacy, with the active involvement of older people, their friends and relatives;

- ensure there are clear, transparent and workable procedures for raising concerns or complaints, both formally and informally, and that these are explained fully to residents/patients and their relatives/friends, verbally and in writing, and displayed prominently and accessibly in the care setting;

- develop systems to identify concerns about repeated, low-level, forms of neglect, including the lateness or omission of a service or care;

- provide clear and accessible information to all staff groups about the organisation's formal and informal complaints procedures and the support they will receive if they use them; this includes protecting staff from fear of unwarranted blame so that they feel confident to raise concerns/issues without fear of reprisal;

- wherever appropriate, implement a 'devolved leadership' approach that supports managers at ward /home level to take responsibility and initiative within clearly defined boundaries and expectations; provide these managers with training and support to develop their leadership capability;

- ensure that all managers recognise their responsibility to actively strengthen the 'change capability' of the care organisation, improving its ability to adapt to external challenge and change;

- ensure that senior management/board meetings routinely receive feedback (including from relatives/friends) on key areas of the patient/resident experience and that these reports are a central focus of organisational decision-making;

- implement a systematic process to ensure the main messages on patient/resident care and other relevant organisational issues from senior management/board meetings are communicated to all staff;

- ensure that the feedback provided by patients/residents (and their relatives/friends) is visibly linked to the development/adjustment of organisational policies and practice.

Care commissioners:

- ensure that care contracts contain a central agreement on the core values of safe and respectful care and the way this will be discharged in their treatment of, and attitude to, residents/patients (and their relatives/families), and also in the support provided to their staff;

- address any inconsistencies in the definitions used by care providers in their safeguarding practice and clinical governance systems, including of "Serious Untoward Incident".

Commissioners/regulators/providers:

- replace 'checklist' based audit and measurement with broader measures that focus on the patient/resident experience and the process of care, as well as its components and outcomes; these measures should be sensitive to omission as well as adverse incidents of care;

- monitor and assess the influence of 'organisational dynamics' in quality assurance/inspection, focusing on the extent to which organisational factors interact to affect the provision of safe and respectful care; involve patients/residents (and relatives/friends/visitors) actively in the process.

Safeguarding bodies/regulators:

- support the collection of returns on safeguarding, including the collection of data on outcomes, to the "Health and Social Care Information Centre"; local data should be brought to the attention of the "Safeguarding Adults Board" so that they can be scrutinised and addressed;

- develop national and local/regional systems for learning from problems/events that have been reported as having led to sub-optimal responses to safeguarding concerns;

- assess the implications for safeguarding of the new NHS bodies including local "Clinical Commissioning Group", "Health and Well-Being Boards", and both local and regional "Quality Surveillance Groups"

- ensure clarity concerning the respective roles of all bodies with safeguarding responsibilities to encourage effective

routine collaboration, responsible collection and management/exploitation of safeguarding data, complaints and other indicators of concern;

- the Care Quality Commission actively to seek out individual complaints and positive feedback and use this information when developing protocols and undertaking inspections.

National health and care bodies:

- review standards on leadership and governance for NHS boards, Clinical Commissioning Groups, and those covered by the "Social care commitment", to be confident that they adequately reflect these bodies' responsibilities to ensure that the values of safe and respectful care are effectively and visibly embedded at all levels within their organisations;

- ensure that relevant NHS data and information systems are effectively 'linked-in' to those of safeguarding bodies, at both local and national levels.

Research community:

- archive relevant data sets and undertake further research on 'definitions and terminology' in collaboration with, and/or validated against the priorities and concerns of, patients/residents, relatives/friends and complainants/'survivors'.

SECTION 6: DISCUSSION - PANICOA IN CONTEXT

INTRODUCTION

The PANICOA studies were largely undertaken between 2010 and 2013 and the policy and the practice context has not been standing still. Significant changes are taking place in adult safeguarding and in the organisation of health and social care services, particularly in England and Wales. There have been a number of influential developments relevant to the PANICOA agenda, notably the Francis Report (2013) and the Government's initial response, *'Patients First and Foremost'* (TSO, 2013). Reports on non-professional hospital staff (Cavendish, 2013) and patient care (Keogh Review, 2013) have also moved the debate forward, as has the work by key groups, such as the Commission on Dignity in Care of Older People (2012), the Nursing and Midwifery Council (NMC, 2009) and the Royal College of Physicians (RCP, 2013). This discussion considers the relevance of the PANICOA findings in this developing policy context.

THE 'BALANCE OF CARE'

The Francis Report (2013) provided a rounded 'deep-dive' examination of the quality of care for all patient groups in one hospital Trust. The Keogh Review (2013) covered more sites but was similarly focussed on the care of patients of all ages. The key questions from these reports are, firstly, how far their findings on the mistreatment of older people (specifically) are common across the health service and, secondly, how far they are also characteristic of the experience of older people in care homes. The PANICOA research throws light on these questions, by examining the occurrence of different types of mistreatment in a wide range of provider 'types' across the UK (see **Annexe 2** for the sampling strategies of the individual studies).

Overall the volume of physical abuse, or harm from assault, reported or observed in the PANICOA studies, was low. This finding needs to be understood in a context where older people, and many of those working with them, are frequently unwilling or fearful of reporting abuse. (It is interesting to note that the few reports of abuse made to the PANICOA researchers by staff members were all of incidents at other care sites.) Physical harm from neglect was evident, however, and the cumulative effect of institutionalised (or serial) neglect was a significant feature, in both care homes and hospitals. There were threats to safety from physical environments unfit for the purpose of caring for older people, especially those with dementia or complex conditions, and risks from the inappropriate care of other residents/patients with challenging behaviour. The experience of emotional neglect, resulting from feeling isolated, ignored or 'powerless', was regrettably common.

When the PANICOA evidence is mapped against the aspirations of a safe and respectful care service for each of the eight care domains of the PANICOA Framework (**Section 3**), it shows that the performance of care providers was significant in its variability. It was generally found to be good, albeit uneven, in the provision of basic 'hands-on' care, suffering more from lack of resources (clean linen, adapted cutlery) and pressures of time than human neglect or error. The continuity and coordination of care and the provision of appropriate information was also generally good, although the PANICOA evidence is less detailed on these two aspects of the care experience. Many older people were being actively engaged in key decisions about their care, but the support for those with cognitive problems or those from minority ethnic communities, was less consistent and

there was some reluctance on the part of hospital staff to be seen to be asking too much of older patients The most reliably poor aspect of care performance was in the maintenance of dignity and privacy in personal care, especially when providing help in using the toilet.

This broad picture appears common to both hospitals and care homes although the latter, perhaps understandably, were generally more likely to provide an appropriate emotional and physical environment for the care of older people. Even here the extent of engagement of residents in the life of the home, and their influence on their care environment, was not extensive. There were good examples of activity and involvement, including of relatives/visitors and more widely, but also much social and emotional isolation. However, acute hospital wards were found to be particularly 'disempowering' spaces for older people, both physically and psychologically, where they were typically made to feel that they were somehow 'in the way' or in the 'wrong place'. In both care contexts, the 'boredom and dejection' of older people appeared common.

Although none of the PANICOA studies set out to provide a statistically sound estimate of overall prevalence, their findings, taken together, provide a sound and extensive evidence-base. The strong correspondence between the main findings of the individual studies suggests that the 'indicative' picture they provide of the overall balance of care, between safe/unsafe and good/poor care, is likely to be typical of the experience of older people in similar institutional care settings.

THE BALANCE OF EXPECTATION

The PANICOA findings are of central relevance to current debates about the expectations that older people can have of institutionally-based care. The financial and demographic context makes a degree of 'trade off' between the ambitions of excellent care and the resource-driven reality inescapable. The key question is where, across all key elements of the care experience, the line between expectations and affordability (or capability) should be drawn. One of the most pressing policy issues is how to ensure a fair and appropriate alignment, or balance of expectations, in the respective expectations of each of the two 'sides' of the central 'exchange relationship': the care 'consumer' on the one hand (the private individual or the public purchaser) and the care 'provider' (the home/owner or hospital/Trust) on the other.

This exchange relationship has two key dimensions: 'cost' and 'quality'. Debates about the cost and funding of care are complex and ongoing. They are largely outside the focus of the PANICOA research, although it picks up a general worry among care home residents about meeting the costs of their future care. The research does, however, inform the important debates about the quality of care and the standards against which this should be assessed and ensured. Work on this issue is being actively led in England by the main regulator, the "Care Quality Commission" (CQC) which has been tasked, following the Francis Report, to develop new standards against which to monitor and assess the performance of providers.

The Francis Report (2013) addressed the issue of care standards and recommended that a distinction be drawn between a 'fundamental' standard of care that would be monitored and enforced, and an 'enhanced' level of care that, significantly, would be subject to the availability of resources. Following the Government's response to this report, the CQC is proposing three categories or 'levels' of care: 'fundamental' (the basics under which no provider can fall without '…facing serious consequences'); 'expected' (what any service user can expect '…as a matter of course'); and 'high quality' (to drive improvement in priority areas and identify excellence). Providers will need to deliver to both 'fundamental' and 'expected' standards in order to meet registration requirements, facing *'…more serious'* consequences if they fail to ensure *'fundamental care'* (CQC, 2013: 14).

This (or any) proposed 'hierarchy of standards' raises important questions about the particular elements, or dimensions, of care that are covered at each level. The CQC is proposing to focus inspection on five key dimensions of care: 'safety'; 'effectiveness'; 'responsiveness'; 'caring'; and 'leadership'. The importance of these broad aspects of the care experience is clearly endorsed by the PANICOA research, which provides insight into the particular aspects of each of these five dimensions that are valued by older people. It indicates that the dimension of 'safety', for example, should include security of personal information and possessions as well as of the person, and should cover emotional as well as physical safety and the harm resulting from cumulative delays or omissions of care. As well as the actions/inactions of care staff (and of relatives/visitors) it would need also to cover the ability of the organisation to protect patients/residents from the harmful effects of their own or others' challenging behaviour.

The PANICOA studies also indicate other aspects of the care experience that are valued by older people but that may be less obviously covered by the CQC's five dimensions. Central to these are the key 'human' areas of self-determination and self-fulfilment. Older people value 'responsiveness' and a 'caring' approach but also, importantly, the opportunity to be actively and meaningfully involved in decisions about their care and to be provided with the right information and support to enable them to do so. They also value the opportunity to be engaged in the world around them, to enjoy social activities, to maintain and develop relationships, and to experience meaning and purpose in their lives. It is not clear how far, if at all, the proposed five dimensions of care will cover these 'softer and subtler' (more "Existential") aspects of care, despite their essential contribution to overall health and well-being.

In addition to questions about the aspects of the care experience covered by the CQC's proposed standards, the PANICOA research raises important issues about how the provision of the five dimensions of care (or others) are assessed. To provide a usable framework to guide inspection, broad concepts such as 'caring' or 'responsiveness' will have to be 'unpacked' into identifiable and measurable parts. As the CQC puts it, the standards will need to be expressed in a way that makes it clear when they have been breached. This is no easy task. Some expectations such as 'safety' appear irreducible, although even here a degree of 'harm' may be inescapable, especially in a clinical context. Other expectations, such as 'neglect' or 'loss of dignity' are less immediately self-evident and will inevitably require the use of qualifiers (such as 'excessive', 'inappropriate' or 'unreasonable') or the use of frequency thresholds to provide a workable basis for assessment.

These issues are especially pertinent to care in institutional settings. For example, the PANICOA research indicates that it is typically not the failure to meet needs, but delay or unreliability in doing so, that undermines the care experience. This raises the question of how much delay, and how often that delay has to be experienced, before it becomes an issue of institutional neglect. And further, how much neglect can be experienced before it is deemed to constitute actual physical or psychological harm. As the PANICOA studies indicate, concepts such as 'neglect' 'harm' and, particularly perhaps, 'loss of dignity', are 'slippery' terms - dependent on the feelings and judgements of those involved and the specific context in which they occur (see **Section 2**).

Perhaps as a result, they found little agreement between relevant care bodies in the way these key terms were defined and used in practice. The studies point to the need for greater 'definitional consensus' on these important terms, if they are to provide a sound basis for policy, regulation and practice. Older people must play an active part in developing this consensus, especially in respect of the 'qualifiers' or thresholds used to establish 'how far' or 'how much' of a particular negative care experience, including its omission, has to occur before it is considered 'mistreatment'.

These debates are not just 'academic'; they have important human implications. Agreement on the different levels or standards of care, and the demarcation between them (what is 'in' or 'out' at each level), will have major consequences for both 'sides' of the care exchange relationship. It will clarify the expectations that older people can reasonably have of their care provider – and that will be underpinned by regulation and, ultimately, law – and those that will be more conditional potentially on the availability of resources. The consequences for care providers will also be different for each level. While breach of 'fundamental standards' will result in prosecution, providers who fail to meet 'expected standards' of care will be formally required to improve, with legal action as a last resort. High-quality care will be an aspiration rather than a requirement. The issue of resources will play a key part in determining the overall 'balance of expectation' that is finally established around the provision of institutionally-based care, as will the pressures on regulators to reduce or streamline the overall volume of regulations. As such, it is essential that the interests of patients and residents are kept centre stage in these debates.

This Report has highlighted aspects of the care experience that are common to both hospitals and care homes. Clearly, there are also very distinctive areas of the care experience that result from the different respective roles and responsibilities of the two different provider sectors. Support to maintain and develop relationships and social/ community engagement, for example, would not be a reasonable expectation of NHS care, given the more 'episodic' nature of hospital stays. It is vital, therefore, that a degree of 'context specificity' surrounds the generation of standards.

Nevertheless, the PANICOA research reveals strong areas of correspondence across the two sectors on the 'care aspirations' for areas such as safety, dignity, privacy, involvement, continuity, information and communication, whether in hospital or care home settings. This suggests that there would be mutual benefit from maximising the 'read-across' in the core standards of a safe and respectful care service, not least in order to provide greater clarity and predictability for residents/patients and their relatives.

THE INFLUENCE OF CULTURE

The PANICOA studies reinforce and inform the growing policy attention being paid to the influence of organisational culture on the quality of institutionally-based care. They delineate the key features of a strong, safe and respectful care culture that is likely to encourage a good quality care experience, for both older people and staff. They suggest that the presence of a strong culture will not prevent mistreatment, but will make it less likely to occur and more likely to be counteracted by other, more positive, organisational influences. By the same token, the studies indicate that a negative overall organisational culture will not necessarily prevent good care but will mean that it will tend to be provided by individuals working against the 'organisational grain', reliant on individual initiative or determination.
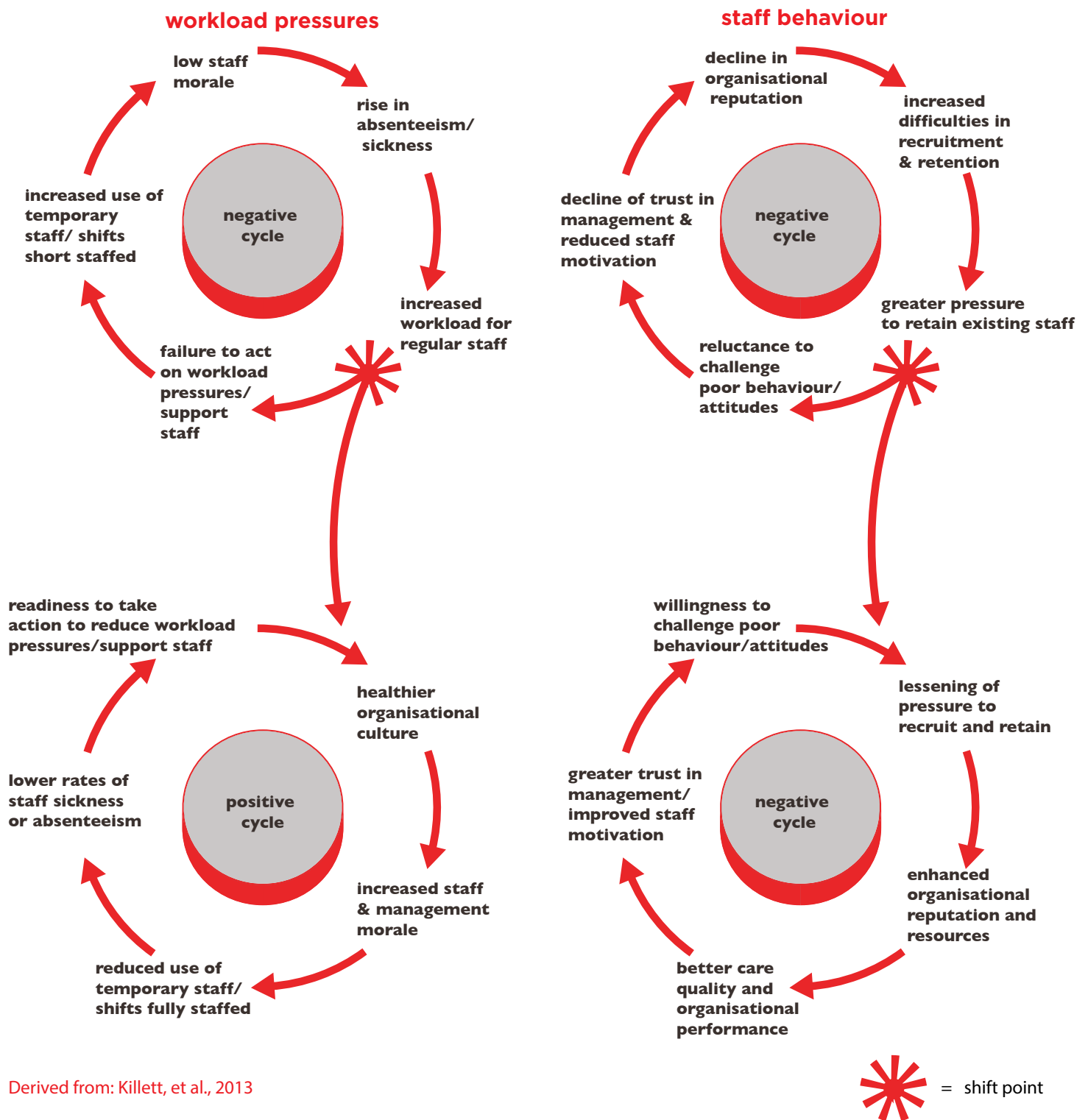
However, importantly, the PANICOA research also indicates that organisational cultures are complex and fluid. In any one organisation there may be a number of different, possibly contradictory, smaller 'sub-cultures' operating at the same time, driven by different values or priorities. The studies show that the interaction between these different sub-cultures will have a crucial influence on the overall performance of the organisation, and that the balance of this 'cultural mix' is likely to change over time.

The overall culture of a particular organisation will also be influenced by external changes and developments. Even in organisations with strong care cultures, new factors, such as high management turnover/absence or unexpected resource pressures, can serve to shift the overall balance of care from good to unstable or inconsistent (or vice versa).

The fact that organisational cultures are not fixed, but are fluid and dynamic, makes it important to identify those areas of activity that have most influence on their overall direction. The PANICOA studies highlight areas where particular forms of organisational action, or inaction, are likely to have significant 'knock-on' consequences for other aspects of the organisation's operation, setting in motion 'virtuous' or 'vicious' cycles of organisational behaviour. For a strong, safe, and respectful care culture, they highlight two key potential 'shift-points': the management of workload pressures, and the response to neglectful or disrespectful staff behaviour. **Fig. 4** (opposite) provides a visual illustration of the positive and negative cycles of organisational behaviour that could be triggered by action (or inaction) around these two areas.

The PANICOA research indicates the importance of monitoring closely these, and other, key shift points when the care organisation may be most susceptible or sensitive to any negative impact from internal or external change. Regularly monitoring activity around the shift-points, it suggests, would increase the capability of the organisation to negotiate any change effectively, and maintain consistently safe and respectful care in the face of new pressures and constraints. Work to strengthen this vital 'change capability' within care provider organisations would clearly be of value to the organisations themselves. The PANICOA evidence indicates that it would also be likely to deliver considerable wider benefit to all bodies with responsibilities for the safe and respectful care of older people.

FIG. 4: POTENTIAL 'SHIFT-POINTS' FOR CULTURAL CHANGE:

workload pressures

low staff morale

rise in absenteeism/ sickness

increased use of temporary staff/ shifts short staffed

negative cycle

increased workload for regular staff

failure to act on workload pressures/ support staff

readiness to take action to reduce workload pressures/support staff

healthier organisational culture

lower rates of staff sickness or absenteeism

positive cycle

increased staff & management morale

reduced use of temporary staff/ shifts fully staffed

staff behaviour

decline in organisational reputation

increased difficulties in recruitment & retention

decline of trust in management & reduced staff motivation

negative cycle

greater pressure to retain existing staff

reluctance to challenge poor behaviour/ attitudes

willingness to challenge poor behaviour/attitudes

lessening of pressure to recruit and retain

greater trust in management/ improved staff motivation

negative cycle

enhanced organisational reputation and resources

better care quality and organisational performance

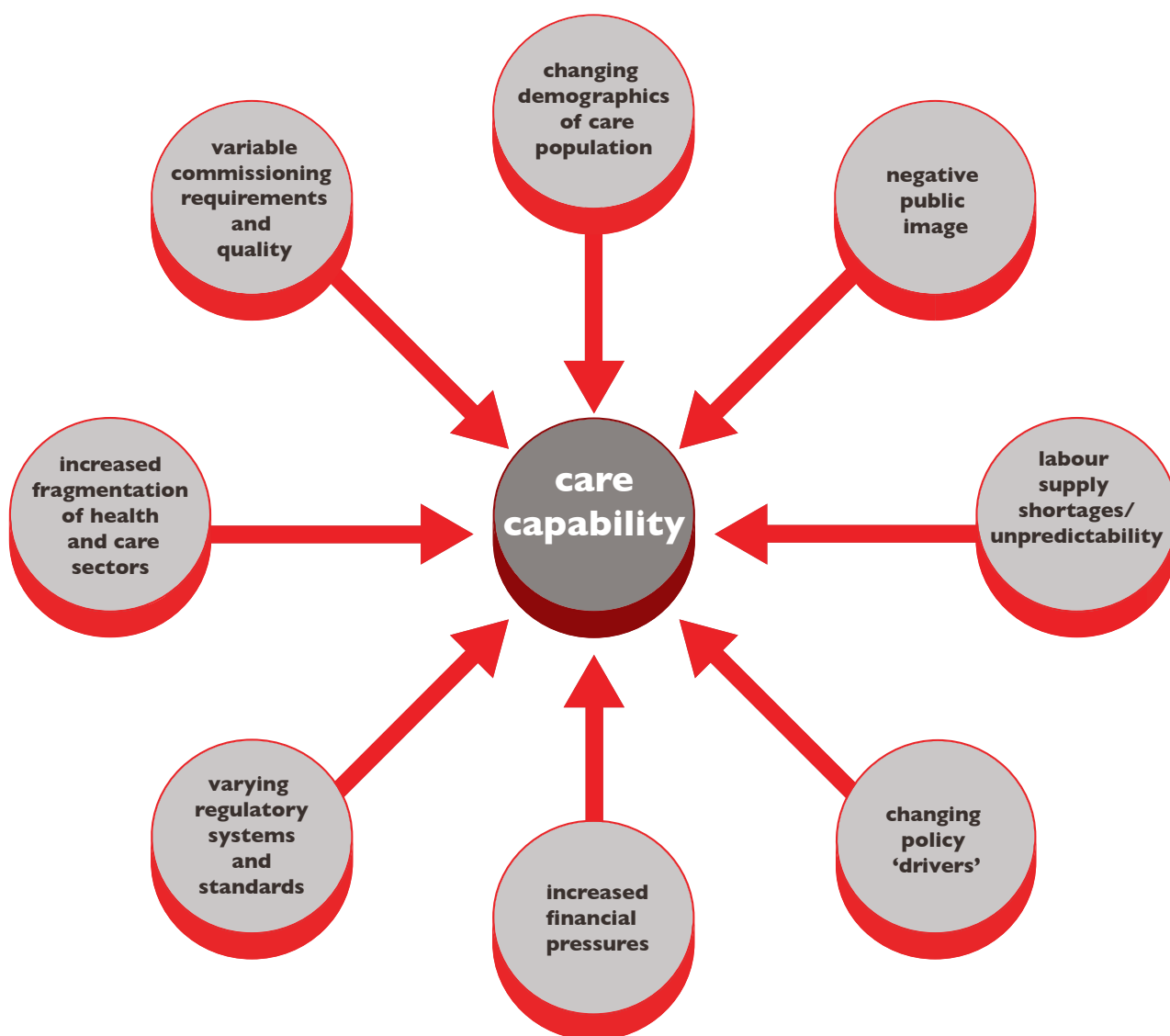Derived from: Killett, et al., 2013

✳ = shift point

THE BIGGER PICTURE

The PANICOA evidence largely focuses on relationships within care provider organisations. It is less extensive on relationships between the range of other bodies with a role in preventing mistreatment in institutional settings, such as the regulators, commissioners and safeguarding bodies. A further Narrative emerged from the PANICOA findings for this wider care community, however, that provides insight into some aspects of the working relationships between its different participants, or 'partners', albeit largely from a provider perspective. Centrally, while this Narrative reflects a broad acceptance of the value of joint- working, it also highlights factors that could serve to undermine its operation or reduce its occurrence.

There were evident areas of operational 'disconnect' between different working parts of the relevant care community,

FIG. 5: INSTITUTIONAL CARE IN A COLD CLIMATE

changing demographics of care population

variable commissioning requirements and quality

negative public image

increased fragmentation of health and care sectors

care capability

labour supply shortages/ unpredictability

varying regulatory systems and standards

increased financial pressures

changing policy 'drivers'

especially around information/data exchange, and a lack of 'read-across' in many key systems and standards. There was only limited exchange of ideas or innovation between health and care home sectors, even around areas of strong common interest such as good safeguarding practice. Culturally, there was an underlying sense of tension, or 'unease' surrounding the inter-connection of key bodies, particularly around safeguarding, but also arising from variability in fee structures and funding arrangements.

Greater emphasis was generally seen to be given to ensuring accountability and compliance, than to providing support and encouraging improvement. This was tending to discourage risk taking and/or innovation and engendering a culture of uncertainty and blame. Care providers in particular appeared to experience the wider care context as a more or less hostile environment, with their work beset by a medley of external challenges. **Fig. 5** provides a visual summary of this 'viewpoint':

The connectivity between different parts of the wider care community was not assisted by organisational 'flux' across the system. Successive waves of reorganisation, most recently from the White Paper *'Liberating the NHS'* (Department of Health, 2010) have injected new bodies, roles and priorities into both care sectors – at local and national levels. These have major implications for existing relations and mechanisms of connectivity, not least in the extra time and resources needed to reconnect and 'realign' following a period of change. The PANICOA evidence suggests that it may be necessary to take steps to preserve existing connections and areas of collaboration relevant to safeguarding older people in institutional care, in addition to developing clear and effective operational links between the (many) new bodies operating in the field.

THE ROLE OF MUTUALITY

It is not just better 'mechanics' that connect organisations, however. A clear sense of common purpose, or 'mutuality', is also necessary to underpin and encourage effective collaboration. The idea of mutuality centres on the recognition of shared or 'reciprocal' interests on the part of the various organisations involved in a shared area of care, and the collective 'value-added' likely to be gained from working more effectively together. This reciprocity of interest is particularly strong for organisations operating within the same sector, such as hospital Trusts or care home providers, where the existence of common interests and shared challenges is most obvious. Development of a greater sense of 'reciprocity of interest' between organisations in different but related sectors, however, such as commissioners and regulators, health/care educators and research funders, could deliver similar mutual benefits.

The PANICOA studies identify a clear sense of tension between care organisations and their staff: a 'them and us' situation, in which the interests of these two 'sides' are seen to be ranged against each other. Yet the research also highlights the strong reciprocity, or 'mutuality' of interest that exists between the organisation and its staff - at all levels. At its simplest, it suggests that staff who feel valued and supported will be more committed to their work and more motivated to pursue the organisation's objectives. The more 'engaged' the staff, the more they will be inclined to stay with the organisation, especially in changing or difficult times.
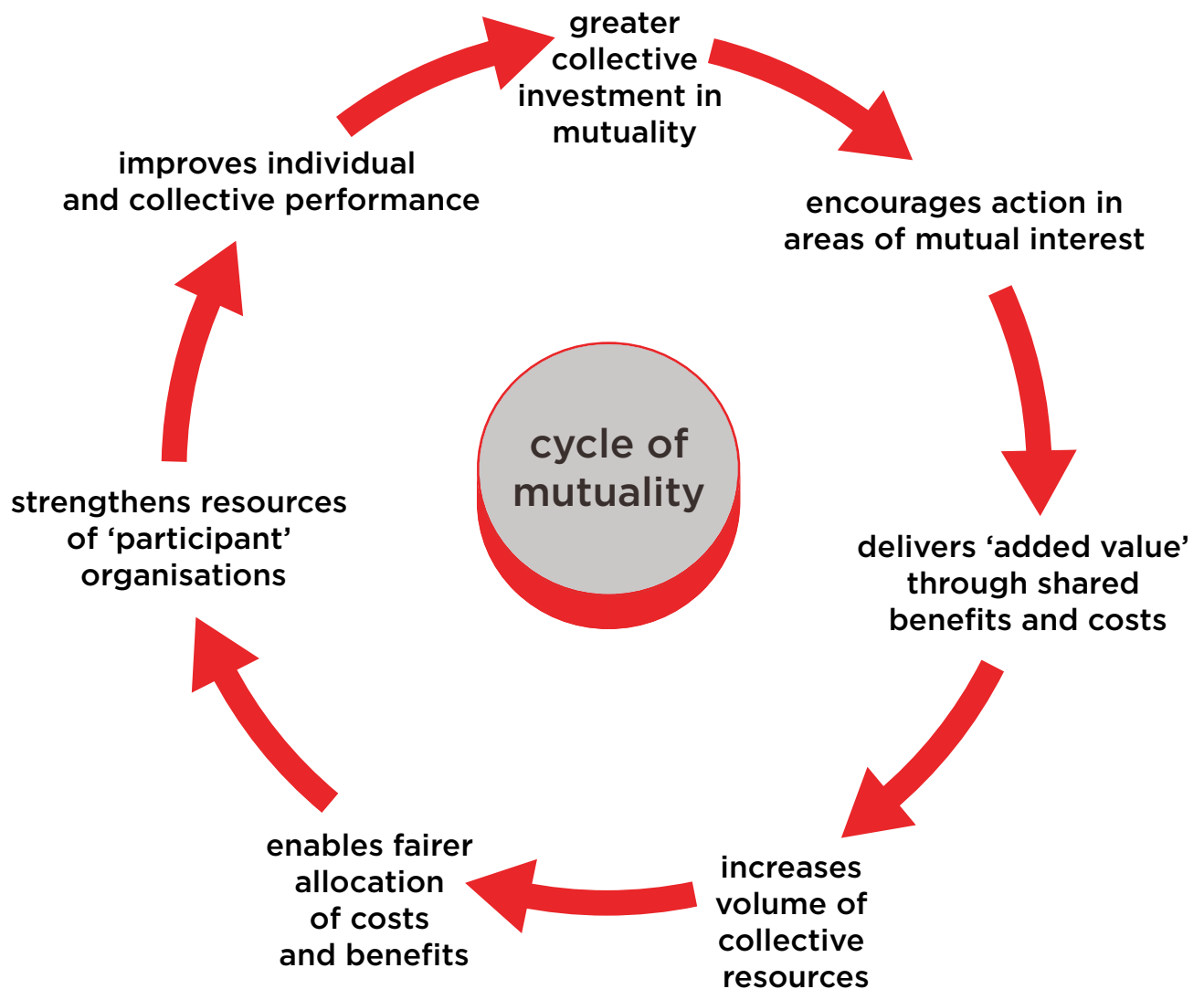
In turn, a more stable and 'contented' workforce is likely to enhance the overall performance of the organisation, improving its reputation and its ability to secure or expand its resources. The PANICOA research indicates that the existence of fair and transparent performance reward systems and a visible

demonstration of concern for staff well-being, in particular, are strongly associated with good organisational cultures. Investment in these and other areas of high mutual interest, therefore, is likely to engender the 'virtuous cycles' of internal behaviour that will add value to the organisation and its work.

The PANICOA research also indicates that the idea of mutuality may have relevance to the operation of the wider care community. As with single organisations, a stronger sense of mutuality could help trigger the 'virtuous cycles' of activity and behaviour that would strengthen collaboration. The identification of areas where joint investment (of time and/or resources) would deliver high mutual benefit, for example, could result in a 'smarter' overall use of available resources. This could ease some of the shared resource pressures and, ideally, encourage a clearer and more consensual allocation of the respective costs and benefits involved in specific areas of joint work. Lessened resource pressures would strengthen the capability of the system as a whole, with positive 'knock-on' consequences for the capability of its parts (individual organisations). And more capable organisations will be more likely to provide a better quality of care. **Fig. 6** (opposite) provides illustration of the 'virtuous cycle' that a stronger sense of mutuality could engender around the use of collective resources:

The PANICOA studies indicate a broad commitment to collaboration and cooperation on the part of care organisations and their staff, even if subject to daily frustrations. The evidence on mutuality is more limited. What evidence there is suggests that, on balance, the sense of mutuality, or common purpose, is underdeveloped - overshadowed by the many areas of dissonance or 'disconnect' that characterise the operation of the wider institutional care community. It is also a concept that is notably absent from current policy and practice debate. Taken together, however, the findings of the PANICOA studies suggest that developing a stronger spirit of mutuality across the care community would prove a positive collective move.

FIG 6: A VIRTUOUS CYCLE OF MUTUALITY

greater collective investment in mutuality

encourages action in areas of mutual interest

improves individual and collective performance

cycle of mutuality

delivers 'added value' through shared benefits and costs

strengthens resources of 'participant' organisations

enables fairer allocation of costs and benefits

increases volume of collective resources

CONCLUSION AND NEXT STEPS

As reflected in this Report, the PANICOA portfolio of research was very wide-ranging. The eleven studies set out to explore the complex issue of mistreatment in institutional settings from a number of different angles, and with a variety of methods. They included both primary research, collecting new data 'in the field', and secondary, or desk-based, studies examining the relevant literature or existing data.

Some studies explored the experience of all older people and staff in particular sites while others focused on specific groups of older people (such as those with advanced dementia or people from minority ethnic communities). One focussed specifically on hospital health care assistants. The nature and influence of organisational culture on the quality of the care experience was the focus of several studies. Together they give in-depth insight into the experience of mistreatment (of both staff and residents/patients) in a wide range of care settings and provide an indicative 'snap-shot' picture against which future progress can be assessed.

Early 'preparatory' studies in the PANICOA portfolio set out to underpin the primary studies and inform research and practice in the field more generally. These highlight the absence of consensus surrounding key concepts such as 'abuse' 'neglect' and 'loss of dignity', and particularly around the understanding and identification of forms of institutional or 'systemic' neglect.

A lack of definitional agreement was also found in the collection of safeguarding data, which is best characterised as a 'jig-saw' of ill-fitting or uncoordinated pieces (**Fig. 2, Section 2**). The need for the relevant organisations to work together more strategically to improve the shared evidence-base underpinning both policy and practice and, in particular, to address

what Manthorpe and colleagues describe as: *'…the endemic problems of confusion of terminology and definitions in this area'* (2011: 65) is a strong conclusion from the early PANICOA studies.

Other preparatory studies assessed the problems and possibilities of undertaking more systematic surveys of prevalence in both care home and hospital contexts. They throw light on ways to address the many practical and methodological issues involved, including the challenge of capturing the experiences of those living with dementia. In doing so, they have helped to prepare the ground for future studies of the prevalence of mistreatment, producing a series of useful tools and guidance to support the process **Annexe 3**.

The need to move forward on this work now seems compelling if we are to establish a sounder evidence-base for practice and policy-making. It is sobering to realise that, despite the strong recommendation of the House of *Commons Select Committee on Elder Abuse* nearly ten years ago (HoC, 2004), we are still no closer to establishing a robust estimate of the true size of this challenging problem.

The primary research studies examined the nature and experience of mistreatment of older people and staff in care homes and hospitals across the UK (although predominantly in England and Wales). This activity involved interviews with a range of participants, covering frontline care staff and managers as well as patients/residents and other stakeholders (regulators/policymakers/user groups), in a total of 74 different care settings, encapsulating over 2,600 hours of observation. The findings from this extensive evidence-base indicate the overall balance of care (in terms of mistreatment) in the contexts studied. These acknowledge evident strengths but

also highlight areas that require policy or practice attention. The main findings from the studies have been drawn together into a series of **Narratives (Section 5),** reflecting different perspectives, or 'viewpoints' on the institutional care experience:

- From the patient/resident viewpoint, there needs to be a stronger focus on preventing the harm resulting from ongoing 'systemic' forms of neglect, including delays and omissions of care, and from the risks created by unsafe or inappropriate physical environments. The need for improved performance on privacy and dignity in personal care (especially in using the toilet) is clearly indicated, in both care homes and hospitals. Disrespectful and ageist attitudes on the part of staff need to be more consistently addressed, especially in hospitals which must become more systematically 'age attuned'.

- Care homes should extend areas of good practice on social engagement and activity, and develop more ways to support older people to retain a sense of purpose and meaning in their lives. The feedback from residents/patients, and their relatives/visitors, should be more actively sought and regularly used by care provider organisations, with clear demonstration of the actions taken as a result. Concerted effort should be made, by all relevant bodies, to raise the expectations that older people and their relatives/friends have of their care in institutional settings.

- From the perspective of care staff, there needs to be better management of workload and resource pressures with more opportunities to develop care skills and practice. Senior managers/owners need to recognise the pressures staff face on a daily basis, particularly those on the 'frontline', who face the very real risk of work-related stress and 'burn-out'. Staff should be protected from verbal or physical aggression from patients/residents and from disrespectful or demeaning treatment by colleagues.

The experience of ethnic minority staff needs specific attention, and acknowledgement should be made of the skills needed to work effectively in multicultural contexts. The performance of all staff would be improved by the better internal flow of relevant information, from the top of the organisation to frontline workers and support staff (and vice versa). Frontline staff, such as health/care assistants, should more routinely be included in care teams and in care planning processes.

- From the viewpoint of the care organisation, there needs to be greater public and policy recognition of the impact of the changing demographics of older populations on their work. Providers are having to care for larger numbers of patients/residents with more complex and challenging conditions, resulting in the need to manage and resource higher-risk care environments. Ongoing problems in staff retention and recruitment, particularly in the care home context, and greater reliance on temporary staff, are increasing workload management pressures.

- Care commissioners should ensure that fee levels adequately reflect these increasing pressures and take more active steps to develop their responsibility for encouraging improvement. Providers would benefit from more support on safeguarding issues from regulators and safeguarding bodies (especially in caring for the increasing number of residents/patients with challenging behaviour) and from greater consistency within, and between, regulatory and commissioning requirements.

These Narratives reflect the contrasting experience of different 'participants' in the care relationship, but they also highlight the many areas of correspondence or 'mutuality' that exist between their respective interests. This 'mutuality of interest' is particularly strong between care staff and those for whom they care,

where it is clear that the good treatment of one is likely to have a positive 'knock-on' influence on the treatment of the other. But the Narratives also identify the many areas of strong mutuality that exist between the business interests of the care organisation and those of its staff, at all levels.

The importance of investment in developing the capabilities of care staff, particularly those working on the front line, but also ward and home managers, emerges strongly from the PANICOA evidence. Such investment is not only in the clear interest of care providers, however; a major conclusion from the PANICOA research is the strong 'added-value' likely to be derived from more collective investment in the 'human capital' of provider organisations, for all those concerned with the care of older people in institutional settings.

The PANICOA research highlights the strong influence of an organisation's culture, both on the care experience of residents/patients and on the 'work experience' of care staff. The studies illuminate the characteristics that will help to ensure and maintain a safe and respectful care culture. Person-centredness will be a core organisational value, visibly demonstrated by staff at all levels of the organisation. Leadership will be strong and dispersed and there will be an active learning culture, making routine use of patient/resident feedback to underpin improvement. Human and other resources will be managed effectively, particularly in the face of external change. Visible efforts will be made to ensure staff well-being and to provide fair and transparent systems for performance reward. Organisations will display strong internal and external 'connectedness'; as the Keogh report put it: *'No hospital, however big, small or remote, will be an island unto itself'* (2013: 11).

The PANICOA studies reveal the fluid nature of organisational cultures, however, and their potential to shift dramatically in the face of new situations or pressures. They indicate the importance of attention being paid, by commissioners and regulators as well as the organisations themselves, to any signs of deterioration or 'ill-heath' in the overall care culture. The studies highlight some of the main areas of organisational behaviour (action or inaction) that are potentially most likely to shift the overall culture of an organisation in positive or negative directions.

For a safe and respectful care culture, they suggest, two crucial 'shift-points' (**Fig. 4, Section 6**) will be the nature of the organisational response to workload pressures and to poor staff attitudes and behaviour. Actively monitoring these and other areas of high cultural 'sensitivity' will improve the ability of the provider organisations to ensure a safe and respectful culture of care.

As well as shedding light on the internal workings of care provider organisations, the PANICOA studies also provide insight into the operation of the wider 'community of interest' operating around care homes and hospitals (commissioners, regulators, local safeguarding bodies etc). They indicate areas of 'disconnection' between the main 'working parts' of this community and the lack of 'read-across' in related aspects of their work. This disconnect is especially evident between health providers and other parts of the system; the need for the NHS to be more effectively 'linked-in' to safeguarding work and to strengthen its engagement with the care home sector are clear messages from the research.

The studies also highlight areas of tension around issues such as fees and funding arrangements, or regulatory and safeguarding activity, that can serve to undermine, or diminish, effective collaboration. The overall 'emotional climate' around joint-working, particularly in safeguarding, is not warm. This leads to the final, and strongest, conclusion to be drawn from the PANICOA research: that of the positive role that a greater sense of mutuality could play in the work of the institutional care community.

The various bodies, groups and agencies that make up the wider care community have a common goal: to ensure the proper care and protection of older people in institutional settings. It seems clear that their separate interests, be they professional, organisational or purely financial, are likely to be served by identifying areas of their inter-operation where the joint investment of time and/ or resources would deliver shared benefits and, potentially, reduced costs. On the basis of the PANICOA findings, these areas of high correspondence or mutuality of interest would seem to include the following three broad areas:

- developing the capability, and increasing the stability, of the health and care workforce, particularly frontline staff and ward/home managers;

- stimulating and supporting the cross-fertilisation of ideas and innovation across (and within) health and care home sectors, especially on good safeguarding practice;

- establishing a stronger 'connectivity' of systems, standards and information (especially in respect of data sources) across the institutional care community, particularly between regulators, commissioners and safeguarding bodies.

The development of a 'mutuality approach', with its emphasis on communality and interconnectedness, may not seem to be facilitated by the greater competitiveness across the health and care sector. But the commitment to a stronger spirit of mutuality - within and between relevant organisations and sectors - could prove to be a significant countervailing influence to the more individualising, or organisationally 'distancing', tendencies at play. Importantly, in a context of general austerity, it could help to ensure a better joint 'husbandry' of scarce human and other resources and avoid the unnecessary waste resulting from duplication of effort. The pursuit of mutuality may be a considerable challenge in the current context but one that, the PANICOA evidence suggests, could prove to be a collectively beneficial step for all involved.

MOVING FORWARD

The Report draws on these conclusions to propose a series of specific recommendations for action by the main organisational 'stakeholders' in the institutional care community. These **Next Steps** are designed to help advance debate and practice on the main issues highlighted by the PANICOA evidence and have been further informed by discussion with relevant experts in the field, including representatives of residents/patients and from the original research teams.

In some cases they are relevant to ongoing work or existing initiatives; where this is the case, the strong message is for a more coordinated and strategic approach to be taken. The recommendations are underpinned by a central theme of mutuality - focussing on the areas of common purpose that the PANICOA research suggests will be most likely to enhance our collective ability to ensure the safe and respectful treatment of older people in institutional care settings.

NEXT STEPS:

Care providers — *senior NHS managers/Board members/care home owners and regional managers*

- Collaborate within their respective (health and care) sectors on the development of a set of standardised 'off the shelf' materials for:
  - the induction and skill 'refreshment' of all staff on the safe and respectful care of older people;
  - the routine collection of patient/resident feedback (and from relatives and visitors);
  - a shared protocol to place an accessible summary of this feedback, and the response of the provider organisation, in the public domain.

Local care commissioners

- In the absence of national standards on staffing levels, work with representatives of local providers to agree a practicable 'staff to patient/resident' ratio sufficient to ensure the safe and respectful care of older people at all times, with particular recognition of the needs of those with delirium or dementia; use this ratio as a basis for developing a fair and accurate fee structure.

- Develop practical ways to encourage greater operational 'connectivity' between local care providers, for example by requiring contracted organisations to engage in a joint approach to information provision/exchange, skill development and clinical/care governance.

Local safeguarding agencies — *Local Safeguarding Adults Boards and Teams*

- Establish a joint mechanism for the routine sharing of information on complaints or concerns in relation to the care of older people in hospitals or homes.

- Support care home/ward managers by disseminating examples of best safeguarding practice and providing advice on safeguarding issues, beginning with guidance on the effective care of those whose behaviour poses risks to themselves or other residents/patients.

National care regulators
(England and Wales)

Care Quality Commission and Monitor **(England)**/*Care and Social Services Inspectorate and the Healthcare Inspectorate,* **(Wales)**/ *Health and Safety Executive and professional regulators/the National Patient Safety Agency*

- Pursue their improvement role more actively by developing ways to support good practice in the care of older people in both hospitals and care homes, including by disseminating examples of excellent and innovatory practice and the use of positive incentives.

- Work with researchers and representatives of the main interest groups, including safeguarding bodies, commissioners and 'experts by experience', to:
  - establish a definitional consensus on key terms, such as 'abuse', 'harm', 'loss of dignity' and 'neglect' (including institutional neglect) and on the way in which their occurrence can most accurately be identified;
  - develop markers of organisational 'fragility' that can be used to help identify provider cultures at risk of resulting in institutional abuse.

- Liaise with representatives of commissioning and safeguarding bodies to maximise the 'read across' in the definitions and measures they use to identify mistreatment, and strengthen the correspondence of definitions and measures used with "AVA" referral data.

- Develop measures to monitor the impact of financial pressures/uncertainty on providers, including assessment of the viability and impact of the contracts let by local care commissioners to care home providers.

- CQC to ensure that the final formulation of the proposed categories of 'fundamental', 'expected' and 'high' care standards captures the priorities of older people as reflected in the **PANICOA** studies and other research, including the need for social engagement and self-affirmation.

- CQC and NICE to maximise the 'read across' between health and social care in the 'fundamental', 'expected' and 'high' care standards and agree a 'single set of core expectations' for ensuring the respect and protection of older people, that are common to care homes and hospitals.

National health and care bodies

National Skills Academy/Skills for Care/Skills for Health/ NHS Commissioning Board/NHS England/Public Health England/ Health and Social Care Information Centre/NHS Trust Development Authority/Professional Standards Authority/ National Patient Safety Agency/ Health Education England

- Ensure that standards of leadership and governance in their respective areas of work reflect a corporate 'commitment to common purpose', including by requiring all relevant bodies to provide an annual account of the way they are discharging this commitment.

- NHS leaders actively to promote a more 'age-attuned' organisational culture across the NHS, beginning with a formal reminder to all health care providers of the need to implement current guidance on the care of older people, and to provide regular reporting of their success in doing so.

- Establish a time-limited working group to produce specific proposals to extend collaboration between the NHS and other parts of the 'institutional care community'; in particular this will aim to;
  - develop proposals to strengthen the connectivity and compatibility of data systems and the cross-fertilisation of ideas and innovation, especially on safeguarding;
  - undertake a wide-ranging review of the engagement of the NHS with the care home sector, including the access of care home residents to local health care services.

National health and care bodies continued…

- Establish a time-limited working group to produce specific proposals to extend collaboration between the NHS and other parts of the 'institutional care community'; in particular this will aim to;
  - develop proposals to strengthen the connectivity and compatibility of data systems and the cross-fertilisation of ideas and innovation, especially on safeguarding;
  - undertake a wide-ranging review of the engagement of the NHS with the care home sector, including the access of care home residents to local health care services.

- Combine and extend ongoing initiatives on the care home workforce into a coherent strategic plan to facilitate:
  - the development of a basic curriculum and minimum training requirements for all care assistants;
  - a career development framework and pay structure for care assistants consistent with that proposed for health care assistants in the Cavendish Report (2013);
  - development of the professional status and standing of care home managers;
  - the feasibility, including costs and benefits, of registration.

- The Health and Social Care Information Centre to lead collective work on the development of a robust, evidence-base (ideally a single UK-wide data-set) on the mistreatment of older people in institutions, including by bringing existing data providers and users together to form a National Safeguarding Data Users Group.

The Government
(Ministers, the Department of Health and other government departments)

- The Department of Health to establish and support a standing care homes forum, including representatives of employers, commissioners, regulators and residents/ relatives, to address the challenges facing the sector, including staffing levels and fee structures, and to identify and promote good practice across the sector.

- Require health and care regulators jointly to consult with relevant interests, including commissioners, employers and resident/patient groups, to agree 'fundamental' and 'expected' standards for minimum staffing levels and to develop proposals for their implementation in both care homes and hospitals, with routine monitoring.

National research funders

- Build on the work begun by the PANICOA initiative to commission a comprehensive longitudinal or time-series survey to provide a rigorous estimate of the prevalence of different types of mistreatment in care homes and hospitals, and to act as a benchmark for future progress. This should ideally be UK-wide as national comparisons will be instructive.

- Meanwhile, actively explore the potential of including key 'marker' questions on mistreatment in existing large population surveys, such as - for those experiencing hospital stays, at least - the English Longitudinal Survey of Ageing (ELSA).

GLOSSARY OF TERMS

Abuse of Vulnerable Adults (AVA):
A mandatory collection which records safeguarding activity relating to vulnerable adults aged 18 and over in England. Information includes the volume of safeguarding activity taking place, the characteristics of adults who may be at risk of harm and the locations in which alleged abuse has taken place. The purpose of the collection is to provide information which can assist stakeholders in recognising and preventing future harm. (Health and Social Care Information Centre (Sept 2013), *Abuse of Vulnerable Adults in England 2012 -13, Provisional Report, Experimental Statistics,* page 4, HSCIC)

Action on Elder Abuse: AEA works to protect, and prevent the abuse of, vulnerable older adults and by doing so also protect other adults at risk of abuse. It was the first charity to address these problems and is the only charity in the UK and in Ireland working exclusively on the issue today. (http://www.elderabuse.org.uk: accessed 04.11.13)

Care and Social Services Inspectorate: Responsible for inspecting social care and social services in Wales to make sure that they are safe for the people who use them. (http://cssiw.org.uk/about/?lang=en: accessed 06.11.13)

Care Quality Commission: Has a role to ensure all care provision, including hospitals and care homes, in England offers safe, effective, compassionate and high-quality care. It currently inspects most hospitals, care homes and domiciliary care services at least once a year, re-inspecting services that aren't meeting standards. Inspections are unannounced unless there is a good reason to let the service know it is coming. (http://www.cqc.org.uk/public/about-us/our-inspections: accessed 04.11.13)

Centre on Policy for Ageing (CPA):
An independent charity promoting the interests of older people through research, policy analysis and the dissemination of information, with the aim of raising awareness of issues around all aspects of ageing and to support good practice. (http://www.cpa.org.uk/cpa/about_cpa.html: accessed 13.11.13)

Clinical Commissioning Group: Since April 2013, CCGs have replaced Primary care Trusts as the commissioners of most services funded by the National Health Service (NHS) in England. They have two important, but distinct, roles: they are responsible for commissioning secondary and community care services for their local populations; and they have a legal duty to support quality improvement in general practice. (Naylor, C., Curry, N., Holder, H., Ross, S., Marshall, L., Tait, E. (2013) Clinical Commissioning Groups: Supporting Improvement in General Practice?, http://www.kingsfund.org.uk/publications/clinical-commissioning-groups:

Collaborative ethnography is an approach to ethnography that deliberately and explicitly emphasises collaboration at every point in the ethnographic process. (Lassister, E. (2005a) quoted in Rappoport, J. (2008) Beyond Participant Observation: Collaborative Ethnography as Theoretical innovation, Project Muse, Vol 1, pp 1 – 31)

Commission on Dignity in Care of Older People: Established in 2012 as part of a joint initiative from the NHS Confederation, Age UK and the Local Government Association (LGA), to help improve dignity in care for older people in hospitals and care homes. (http://www.nhsconfed.org/priorities/Quality/Partnership-on-dignity/Pages/Commission-on-dignity.aspx: accessed 04.11.13)

Community of purpose: A community of people who are going through the same process or are trying to achieve a similar objective. Such communities serve a functional purpose, smoothing the path of the member for a limited period surrounding a given activity. (http://en.wikipedia.org/wiki/Community_of_purpose: access 04.11.13)

Cultural capital: The non-financial social assets that promote social mobility beyond economic means, such as education, intellect, style of speech, dress, and even physical appearance. (https://www.boundless.com/sociology/definition/cultural-capital: accessed 04.11.13)

Empirical (studies/investigations)**:** Knowledge is validated through sense experience, or through the surrogates of scientific instrumentation, which in the social sciences would include survey questionnaires and interview data. (Malcolm Williams: http://srmo.sagepub.com/view/the-sage-dictionary-of-social-research-methods/n63.xml: accessed 04.11.13)

English Longitudinal Survey of Ageing: An English survey that collects data from a representative sample of the English population aged 50 and older: the data are both objective and subjective relating to health and disability, involving biological markers of disease, economic circumstance, social participation, networks and well-being. (http://www.ifs.org.uk/ELSA/about: accessed 04.11.13)

Ethnography: A research design with an assumption that personal engagement with the subject is the key to understanding a particular culture or social setting.

Existential: Relating to, or dealing with, existence, especially with human existence. (https://www.vocabulary.com/dictionary/existential: accessed 6.11.13)

Friends and family test: In order to improve services, since 2013 patients are asked, within 48 hours of discharge, to give a judgement on the care and treatment they received. (http://www.nhs.uk/NHSEngland/AboutNHSservices/Pages/nhs-friends-and-family-test.aspx: accessed 04.11.13)

Health and Safety Executive: The national independent watchdog for work-related health, safety and illness. It is an independent regulator and acts in the public interest to reduce work-related death and serious injury across Great Britain's workplaces. (http://www.hse.gov.uk/aboutus: accessed 06.11.13)

Health and Social Care Information Centre: The national provider of high-quality information, data and IT systems to health and social care organisations so they can provide better services and improve health standards. (http://www.hscic.gov.uk: accessed 04.11.13)

Health and Well-Being Boards: Established under the Health and Social Care Act 2012, they act as a forum where key leaders from the health and care system work together to improve the health and well-being of their local population and reduce health inequalities. As a result, patients and the public should experience more joined-up services from the NHS and local councils in the future. (http://www.local.gov.uk/health/-/journal_content/56/10180/3510973/ARTICLE: accessed 04.11.13)

Healthcare Inspectorate Wales: The independent inspectorate and regulator of all healthcare in Wales. (http://www.hiw.org.uk: accessed 016.11.13)

Health Education England: The NHS engine that facilitates a better health and healthcare workforce for England. It is responsible for the education, training and personal development of every member of staff, and recruiting for values. (http://hee.nhs.uk: accessed 04.11.13)

Human capital: In an organisational context, human capital refers to the collective value of the organisation's intellectual capital (competencies, knowledge, and skills). (http://www.businessdictionary.com/definition/human-capital.html: accessed 04.11.13)

Ideal-typical: The 'ideal typical' is a mental construct derived from observable reality, although not conforming to it in detail because of deliberate simplification and exaggeration. It is not ideal in the sense that it is excellent, nor is it an average; it is, rather, a constructed ideal used to approximate reality by selecting and accentuating certain elements. http://www.britannica.com/EBchecked/topic/281796/ideal-type.

Independent Safeguarding Authority: The ISA was created to help prevent unsuitable people from working with vulnerable adults or children. In December 2012, it merged with the Criminal Records Bureau (CRB) to form the Disclosure and Barring Service (DBS). (http://www.criminalrecordchecks.co.uk/isa-independent-safeguarding-authority.htm:

https://www.gov.uk/government/organisations/disclosure-and-barring-service: accessed 04.11.13)

Indicative: Referring to an 'indicator' which 'stands in' or substitutes, in some sense, for something less readily measurable. (Roger Sapsford: http://srmo.sagepub.com/view/the-sage-dictionary-of-social-research-methods/n98.xml: accessed 04.11.13)

Institutional settings (institutionally-based care)**:** Whilst acknowledging that the term 'institutional care' has had negative or 'controlling' associations in the past, it is used here - for brevity - as a neutral descriptive term that refers collectively to both hospital and care/nursing home establishments.

Keys for Care: Created by the Relatives & Residents Association in 2013, (http://www.relres.org) and supported by Comic Relief, a *"...practical, authoritative and jargon-free, ... set of 12 keys (which) have been put together by people who live and work in homes and offer an encouraging and confidence-building support for induction and training programmes, or simply as a trigger to discussion."* (http://www.relres.org/products-resources/keys-to-care-publicity-order-form.html: accessed 04.11.13)

Local Authority commissioning staff: Responsible for commissioning and collaborating on a range of public health services and for advising the commissioners of local NHS service. (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212962/Public-health-intelligence-local-government-functions.pdf: accessed 04.11.13)

Local Safeguarding Adult Boards: Local Authority Boards with the role of coordinating and ensuring the effectiveness of local services in order to protect local adults. (http://careandsupportbill.dh.gov.uk/safeguarding-adults-at-risk-of-abuse-or-neglect/clause35: accessed 04.11.13)

Longitudinal studies: Any social or developmental research involving the collection of data from the same individuals (or groups) across time. Observing change in these individuals gives a better basis for causal inference than a cross-sectional study, because of the temporal sequencing involved. (John Bynner: http://srmo.sagepub.com/view/the-sage-dictionary-of-social-research-methods/n111.xml?rskey=FOpEjt&row=3: accessed 04.11.13)

Mental Capacity Advocate Service: Introduced under the Mental Capacity Act 2005, the role of the independent mental capacity advocate (IMCA), which offers a legal safeguard for people who lack the capacity to make specific important decisions, including making decisions about where they live and about serious medical treatment options. (http://www.scie.org.uk/publications/imca: accessed 04.11.13)

Monitor: The regulator for health services in England which aims to protect and promote the interests of patients by ensuring that the whole sector works for their benefit. (http://www.monitor-nhsft.gov.uk: accessed 04.11.13)

Multivariate logistic regression: Multivariate statistics is a form of statistics encompassing the simultaneous observation and analysis of more than one outcome variable. Multivariate regression analysis attempts to determine a formula that can describe how elements in a vector of variables respond simultaneously to changes in others. For linear relations, regression analyses here are based on forms of the general linear model. (http://en.wikipedia.org/wiki/Multivariate_statistics: accessed 05.11.13)

Narrative: Referring to a family of approaches to diverse kinds of texts, which have in common a storied form. Events are selected, organized, connected and evaluated as meaningful for a particular audience. (Catherine Kohler Riessman: http://srmo.sagepub.com/view/the-sage-dictionary-of-social-research-methods/n124.xml: accessed 04.11.13)

National Data Archive: A resource for researchers, teachers and learners, being the largest collection of digital data both historical and contemporary in the social sciences and humanities in the United Kingdom. (http://data-archive.ac.uk: accessed 04.11.13)

National Confidential Enquiry into Patient Outcome and Death: Supports hospitals and doctors to deliver safe patient care by publishing reports with information about the practical management of patients. (http://www.ncepod.org.uk: accessed 04.11.13)

National Skills Academy: An employer-led membership organisation, created by social care employers, to transform the quality of leadership, management, training, development, and commissioning. (https://www.nsasocialcare.co.uk/about-us: accessed 06.11.13)

Naturalistic: The form of records of human activities that are neither elicited by nor affected by the actions of social researchers. (Jonathan Potter: http://srmo.sagepub.com/view/the-sage-dictionary-of-social-research-methods/n126.xml: accessed 04.11.13)

NHS Commissioning Board: Established in October 2011 to design the proposed commissioning landscape and develop its business functions. (http://www.england.nhs.uk: accessed 04.11.13)

NHS England: The main aim of NHS England is to improve the health outcomes for people in England. (http://www.england.nhs.uk: accessed 04.11.13)

NHS Incident Reporting Systems: The National Patient Safety Agency has developed a national framework for serious incidents in the NHS, titled 'National Framework for Reporting and Learning from Serious Incidents Requiring Investigation'. The framework is also the first stage in the development of a consolidated Serious Incident Management System that will replace the current Strategic Executive Information System (STEIS) serious untoward incident system in 2010. http://www.nrls.npsa.nhs.uk/report-a-patient-safety-incident/serious-incident-reporting-and-learning-framework-sirl

NHS Trust Development Authority: Provides leadership, support and development for those providers that remain NHS Trusts. (http://www.ntda.nhs.uk: accessed 04.11.13)

NICE guidance: Supports healthcare professionals and others to ensure health and social care is of the best possible quality and offering best value for money. (http://www.nice.org.uk: accessed 04.11.13)

Participant observation is the most common component of ethnography which can also involve interviews, conversational analysis, documentary analysis, film and photography, life histories. (Dick Hobbs: http://srmo.sagepub.com/view/the-sage-dictionary-of-social-research-methods/n70.xml: accessed 04.11.13). It differs from 'non-participant' observation in that the researcher is actively involved in the situation/process being studied, rather than acting as a detached, dispassionate, observer.

PIECE-dem: Developed by the University of Worcester, an observational process that illuminates the experience of those people with advanced experience of dementia and high levels of need, who are most vulnerable in long-term care settings to experiencing a poor quality of life. (http://www.worcester.ac.uk/discover/dementia-piece-dem.html: accessed 04.11.13)

Professional Standards Authority: Aims to be a strong, independent voice for service users and the public in the regulation of health and care professionals throughout the UK. (http://www.professionalstandards.org.uk: accessed 04.11.13)

Public Health England: Has the mission is to protect and improve the nation's health and to address inequalities. (https://www.gov.uk/government/organisations/public-health-england/about: accessed 06.11.13)

Quality Surveillance Groups: From April 2013, a network of QSGs was established across the country to bring together different parts of health and care economies locally and in each region in England, to routinely share information and intelligence to protect the quality of care patients receive. (https://www.gov.uk/government/publications/how-to-establish-a-quality-surveillance-group-guidance--2: accessed 04.11.13)

Safeguarding Adults Board (SAB): Established in all England (and most Wales) local authorities following the publication of No Secrets (Department of Health, 2000), with the aim of creating a framework within which all responsible agencies work in partnership to ensure coherent inter-agency policies and procedures for the protection of vulnerable adults, and to ensure that these are implemented locally. The partnership includes the public, voluntary agencies, and the public and private sector.

Serious Case Reviews: The purpose of the SCR is to learn lessons from a local incidence of adult abuse in order to improve local inter-agency practice. (Manthorpe, J., and Martineau, S., 2010 Serious Case Reviews in Adult Safeguarding in England: An Analysis of a Sample of Reports, (*British Journal of Social Work:* http://bjsw.oxfordjournals. org/content/early/2010/09/01/bjsw. bcq100: accessed 04.11.13)

◀ **Serious Untoward Incident:** A term frequently used in relation to medical incidents, relating to a national framework for serious incidents (developed by the National Patient Safety Agency) following consultation with (amongst others) the Care Quality Commission, the Department of Health, Medicines and Healthcare products Regulatory Agency, the NHS Litigation Authority, Monitor and the Independent Advisory Service. (http:// www.nrls.npsa.nhs.uk/report-a-patient-safety-incident/serious-incident-reporting-and-learning-framework-sirl: accessed 04.11.13)

Skills for Care ensures that England's adult social care workforce has the appropriately skilled people in the right places working to deliver high-quality social care. To achieve this, it focuses on the attitudes, values, skills and qualifications people need to undertake their roles. (http://www. skillsforcare.org.uk/About-us/About-us. aspx: accessed 06.11.13)

◀ **Social care commitment:** An agreement about workforce quality between all parts of adult social care in England, with a primary purpose to ensure public confidence that people who need care and support services will always be supported by skilled people who treat them with dignity and respect. https://www. thesocialcarecommitment.org.uk: accessed 04.11.13)

Time-series survey: A research design in which measurements of the same variables are taken at different points in time, often with a view to studying social trends. They are distinguishable from 'one-shot' cross-sectional designs in which measurements are taken only once. (Victor Jupp: http:// srmo.sagepub.com/view/the-sage-dictionary-of-social-research-methods/ n208.xml: accessed 04.11.13)

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