



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** Summary Report



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.

DISCLAIMER

'**Respect and Protect**' is an independent Report. It draws on the eleven PANICOA research studies, but its interpretations and conclusions are those of the authors and not necessarily those of the funders Comic Relief and the Department of Health nor the researchers themselves.

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This report draws on the eleven PANICOA studies within the PANICOA Research Initiative. This was funded by the Department of Health and Comic Relief. The full PANICOA report can be downloaded at: www.panicoa.org.uk

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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 5 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 (Preventing the abuse and neglect in the institutional settings 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

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 community¹. Eleven studies were commissioned under the initiative, completing between 2009 and 2013.

The aims of the PANICOA Research Initiative were threefold:

- 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.

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 or patients was not covered.

The PANICOA initiative was also broad in focus, including both care homes (nursing and residential) and hospitals (general and older adult wards); care staff as well as older people (and their relatives/visitors); 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 adopted a portfolio approach, commissioning a range of studies to examine the complex issue of mistreatment from different angles and with a variety of methods. The final PANICOA Portfolio contains eight primary research studies, investigating the experience of all, or specific groups of, older people and staff, including patients/residents with advanced dementia and those from minority ethnic communities. Three secondary, or desk-based, studies explored the definitional and methodological issues involved in identifying and measuring mistreatment, and assessed the quality of 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 involve a range of different types of care provider and geographical locations across the UK, although largely in England and Wales. Overall, the evidence is more extensive on the experience of older hospital patients and care home residents, and on the views of frontline staff and middle managers, than on those of more senior staff.

The PANICOA research provides insight into the nature and 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 individual studies suggests that the composite picture they provide is likely to be broadly indicative of the situation in care homes and hospitals more widely.

WORKING METHOD

A conceptual framework was developed to combine and organise the evidence from the individual studies. **The PANICOA Framework** drew on the priorities of older people (and relatives/visitors) and staff, as reflected in the research, to identify eight core elements or 'domains' of the overall care experience: 'direct care'; 'safety and security'; 'dignity and respect'; 'continuity and coordination'; 'involvement and control'; 'communication and information'; 'community and relationships'; and 'identity and meaning'.

For each domain, existing standards and guidance were drawn upon to produce a series of policy 'aspirations', indicating the desired features of that particular aspect of the care experience. The findings of the studies were mapped against these aspirations, identifying areas of relative strength and weakness in the performance of both care homes and hospitals.

In analysing the findings, priority was given to findings that were reinforced by more than one of the individual studies.

The combined findings from the individual studies were used to identify particular aspects of the overall care experience that would benefit from policy and/or practice attention. These informed two **Templates for Good Practice**, covering specific actions necessary (although not necessarily sufficient) to ensure a 'respect and protect' care service and care culture. The templates will, in many cases, confirm and reinforce already established good practice in hospitals and care homes. As such, they provide a framework to assist regular report and review. Where this is not, or not wholly, the case, the templates may serve as a guide for future service improvement. They are provided in the full **PANICOA Report**².

The main findings from the PANICOA studies were brought together to construct a series of 'ideal-typical'³ **Narratives**, illustrating the experience of the 'care relationship' from three different key perspectives or 'viewpoints': the resident or patient (and relatives/friends/visitors); care staff (including managers and care professionals); and care provider organisations (hospitals and care homes). A fourth Narrative was also discernible, albeit less distinctly, characterising the operation of the different parts of the wider 'institutional care community' (other health or care home providers, commissioners, regulators and local safeguarding bodies).

THE PANICOA NARRATIVES

THE RESIDENT/PATIENT NARRATIVE

From the perspective of the residents and patients involved, the following 'headline picture' emerged from the combined PANICOA studies:

- the provision of **direct 'hands-on' care** was generally good, although uneven, but suffered from a lack of resources (clean linen, adapted cutlery) and pressures of time;
- the overall volume of **physical abuse**, reported or observed, was low but physical harm from **neglect** was evident, and the cumulative effect of institutionalised (or serial) neglect was evident, in both care homes and hospitals;
- there were risks to **safety and security** from physical environments ill-suited to the purpose of caring for older people, especially those with dementia or complex conditions, and 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, and the disrespectful treatment of residents/patients, involving patronising or 'infantilising' **communication**, was prevalent in both care contexts;
- the **continuity and coordination** of care and the provision of appropriate information to underpin choice appeared generally good, although there was less information from the studies on these aspects of the care experience;
- the extent to which individuals were **actively engaged** in decisions about their care was reasonably good, and there was evidence of particular efforts being made with those with special communication needs;

- the weakest areas of care performance related to the maintenance of **dignity and privacy** in personal care, most notably in using the toilet, and in supporting the social engagement of older people and their need for meaning and purpose in their lives.

The broad picture was common to both hospitals and care homes, although the latter were generally more likely than hospitals to provide an appropriate environment for the care of older people and to relate to them with dignity and respect. Even in care homes, however, the extent of engagement of residents in the life of the home, and their influence on their care environment, was not extensive. Acute hospital wards were found to be particularly 'disempowering' spaces for older people, both physically and psychologically.

The studies also indicate that older people generally did not have very high expectations of their care and that their relatives considered that regulatory standards were set too low. Patients and residents, especially those from minority ethnic communities, were generally hesitant to raise concerns or to complain: the few who had done so had met with largely defensive responses. All sites studied had formal processes for making complaints but it was not easy, in either care setting, for patients/residents (relatives/visitors) - or staff - to report repeated breaches of safety and security arising from 'normalised' organisational practices that could be considered cumulatively neglectful.

THE CARE STAFF NARRATIVE

Professional and frontline staff were typically hardworking and committed to delivering respectful care that supports the independence and self-determination of patients and residents. They recognised 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. At times, however, health professionals were concerned not to place too much responsibility onto patients. While staff generally were seen to value good relationships with older people, they could at times find it necessary to distance themselves from patients or residents in order to accomplish emotionally difficult tasks.

Staff were frequently frustrated in providing good care by constraints of time, resources and the physical environment. Pressures of time, in particular, resulted in 'reactive' care that reduced the opportunity for the informed participation of older people. High levels of staff turnover and/or absenteeism, and heavy dependence on temporary staff, served to undermine the continuity and coordination of care and produce a more fragmented care experience. Typically, much basic 'hands-on' care was undertaken as a series of unrelated 'tasks' performed by less experienced/qualified staff who had little or no involvement in the care planning process. These 'frontline' staff, especially in hospitals, considered that they had little opportunity to share their knowledge or concerns about 'their' patient or resident with more senior colleagues.

Care staff were themselves frequently at risk of verbal or physical mistreatment, 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 was not uncommon, and personal strategies to manage stress were leading staff to disengage from patients/residents. Under pressure, priority was given to meeting urgent physical needs at the cost of providing more relationship-centred care. The ability of staff to respond effectively to the changing circumstances and needs of older people was frequently seen to be frustrated by inflexible organisational routines and systems.

The overall level of job satisfaction for care assistants in wards or care homes was low, although higher for hospital nurses. Health care assistants, in particular, considered that their role was seldom affirmed by the wider care team and experienced a general sense of 'disempowerment'. Staff were keen to develop their skills and capabilities but the opportunities to do so were limited and widely considered unsatisfactory. In both care homes and hospitals staff felt excluded from key information, especially about organisational change, but also on individual patients/residents. Managers were typically seen to lack understanding of the daily pressures staff faced and were not fully supportive – particularly when things went wrong.

THE CARE ORGANISATION NARRATIVE

Health and care providers were experiencing a number of significant, and ongoing, challenges. The greater number of older people living longer with dementia or other cognitive impairments, and/or multiple conditions, was necessitating the provision of 'higher-risk' care environments - a particular challenge for care home providers. Financial constraints across the health and care sector were putting pressure on resources, especially for care homes with large numbers of publicly funded residents. Recruitment and retention difficulties were common. This was particularly so in care homes, but budgetary constraints in some hospital wards were resulting in 'untenable' staffing levels. High levels of staff turnover, necessitating greater use of temporary or agency personnel (including many without English as a first language), were exacerbating workload management pressures.

Health/care commissioners were not generally seen to acknowledge these challenges in the level of funding, support or resources given to providers. Regulation was 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. Both regulatory and safeguarding processes were widely seen to focus more on ensuring accountability and, ultimately, apportioning blame than on providing support and assisting improvement. Care home providers, in particular, tended to feel they were operating in a generally hostile environment, with their work not well understood or fairly regarded by government, regulators or the public more widely.

Care provider organisations varied in their ability to mediate, or 'buffer', the impact of these pressures in the interests of their patients or residents. In many, this 'capability for change' was being constrained by entrenched systems or inflexible ways of working. In the NHS, in particular, a focus on practice audits and risk management strategies was seen to be encouraging more defensive and 'risk-averse' organisational cultures, reducing the potential for professional judgement or individual initiative. The structure and organisation of hospitals, and particularly the emphasis on medical specialities, had typically not risen to the challenge of meeting the increasingly complex needs of older people, despite the latter being their main patient population group.

The quality of leadership, across both health and care home sectors, was of uneven strength and visibility. Hierarchical organisational structures were common, with little downward dispersal of authority and only limited established team-working between senior and frontline staff. The autonomy of ward and, particularly, care home managers was notably limited. Internal communication was not an evident strength, with many organisations, especially hospitals, lacking effective or routine systems for transmitting essential information to staff at all levels. There was considerable variation in the extent to which care homes had developed a culture of 'activity and involvement' associated strongly with the delivery of safe and respectful care in institutional settings.

THE 'CARE COMMUNITY' NARRATIVE

The final narrative concerned the operation of the wider community of organisations with (various) responsibilities for the care and protection of older people in institutional contexts, seen largely from a provider perspective. This indicates 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 was not so evident, however, with only limited cross-fertilisation of good practice, particularly on safeguarding, between organisations working in different sectors of the institutional care community.

The distinctive roles and responsibilities of different bodies were not always mutually clear, with a lack of 'read across' or 'disconnect' in relevant systems or practices, particularly between those of health providers and other parts of the institutional care system. There was only limited exchange of information on complaints and concerns between relevant organisations, especially between the different (health and care) regulators and between regulators and safeguarding bodies. The evidence-base underpinning policy and practice was uncoordinated and inconsistent, involving a wide variety of sources collecting a range of different data, underpinned by 'endemic problems of confusion of terminology and definitions'⁴.

There were underlying tensions or areas of 'dissonance' across the institutional care sector arising from the uneven distribution of 'opportunities and costs' between different groups of both providers and patients/residents. These were particularly around safeguarding and regulatory practice, but also on areas such as workforce training, assessment thresholds, and funding structures/levels. The overall 'emotional climate' around the institutionally-based care of older people was generally negative, fuelled periodically by the wide-ranging 'fall-out' from specific adverse events.

CONCLUSIONS AND RECOMMENDATIONS

Drawing the Narratives together highlighted specific areas of the institutional care experience that would benefit from policy and practice attention.

ON THE EXPERIENCE OF RESIDENTS AND PATIENTS

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 when 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, particularly in hospitals which must become more systematically 'age attuned'. Care homes should develop further ways to ensure the social engagement of residents and to support them to retain 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.

ON THE EXPERIENCE OF CARE STAFF

There needs to be better management of workload pressures and more opportunities for staff to develop skills and improve practice. Senior managers/owners need to recognise the pressures staff face on a daily basis, particularly those on the 'front line', including the very real risk of work-related stress and 'burn-out'. Staff should be protected from verbal or physical harm from patients/residents (or relatives/visitors) and from disrespectful or demeaning treatment by colleagues. The experience of ethnic minority staff requires specific attention, and acknowledgement

should be made of the skills needed to work effectively in multicultural contexts. The performance and engagement of all staff would be enhanced 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.

ON THE EXPERIENCE OF CARE PROVIDER ORGANISATIONS

There needs to be greater public and policy recognition of the impact on providers of the changing demographics of older populations. Care commissioners should assess how far current funding levels adequately reflect the increased challenges experience by care providers. They should also take more active steps to develop their formal responsibility for encouraging improvement in their contractor base. 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.

More attention should be given by regulators, commissioners, as well as providers themselves, to the organisational culture of homes and hospitals. The nature of an organisation's culture (or behaviour) was found to be a strong determinant of the quality of the care experience, for staff as well as older people.

The manner in which the organisation treats its human resources will be pivotal: the good treatment of staff will be likely to result in the good treatment of those for whom they care. Visible concern for the well-being of staff, the existence of fair and transparent reward systems and a culture of trust and openness were all factors found to be strongly associated with a safe and respectful care environment - for both staff and patients/residents.

The PANICOA studies also revealed the inherently volatile nature of organisational cultures and their ability to shift markedly in the face of change. Certain areas of organisational action (or inaction) may be particularly sensitive ‘shift-points’, decisively nudging the internal culture in a positive or negative direction and creating ‘vicious’ or ‘virtuous’ cycles of organisational activity. For a safe and respectful organisational culture, the management of workload pressures and the response to neglectful or disrespectful behaviour emerged as two important potential shift points. Regulators and commissioners should monitor these, and identify other, key cultural ‘markers’ more actively in order to identify and support organisations that are at risk of developing an unsafe or disrespectful care culture.

ON WORKING TOGETHER

The PANICOA findings indicate the need for the relevant organisations to align systems, standards and, especially, information collection. The NHS, in particular, must be more effectively ‘linked-in’ to safeguarding work and take steps to strengthen its engagement with local care home providers. More effort should be made to identify and share good practice, ideas and innovation across the institutional care community, particularly on safeguarding and on strengthening the ‘change capability’ of provider organisations. The importance of more collective, strategic work to improve the shared evidence-base underpinning a safeguarding policy and practice is a strong conclusion. Successive waves of reorganisation have injected new bodies, roles and priorities into both care sectors – at local and national levels. Effort is needed to preserve existing connections and areas of collaboration (especially on data collection), as well to develop effective operational links between the (many) new organisational ‘players’ in the field.

It is not just better ‘mechanics’ that connect organisations, however. A sense of common purpose, or ‘mutuality’, is also necessary to underpin and encourage effective collaboration. This centres on the recognition of shared or ‘reciprocal’ interests on the part of the various organisations involved in a common area of work, and the collective ‘value-added’ likely to be gained from working more effectively together. This mutuality of interest is particularly strong for organisations operating within the same sector, such as hospital Trusts or care home providers, where the existence of shared interests and common challenges is most obvious. The PANICOA findings also suggest however that the development of a greater sense of mutuality between organisations in the wider institutional care community could be mutually beneficial.

The various bodies, groups and agencies that make up this wider ‘community of interest’ have a common goal: to ensure the proper care and protection of older people in institutional settings. Yet while a general commitment to collaboration and cooperation is evident (even if subject to daily frustrations), the composite picture from the PANICOA studies indicates that the sense of mutuality - or common purpose - appears underdeveloped, overshadowed by the many areas of dissonance or ‘disconnect’ that characterise the operation of the wider care community. The overall impression is of considerable formal distance between different bodies with strong complementary interests, (such as regulators and commissioners) and only limited joint work to support or strengthen core parts of the system (such as care staff or provider organisations).

The PANICOA findings indicate three broad areas of high correspondence or ‘mutuality’ of interest where the collective investment of time and/or resources would be likely to deliver strong ‘added value’:

- developing the capability, and increasing the stability, of the health and care workforce, particularly of frontline staff and ward/home managers;
- stimulating greater cross-fertilisation of ideas and innovation across the health and care system, especially on good safeguarding practice;
- establishing stronger ‘connectivity’ of systems, standards and information between the different working parts of the relevant 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 increased spirit of competitiveness across the health and care sector. But the commitment to a stronger ethos of mutuality, within and between relevant organisations and sectors, may prove to be a significant countervailing influence to the more individualising, or organisationally ‘distancing’, tendencies at play. Importantly, in a context of overall austerity, it could help to ensure a better joint ‘husbandry’ of scarce human and other resources and avoid the wasteful 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.

Drawing on the combined findings from the PANICOA studies, and considering them in the current policy context, the main report concludes with a series of practical actions or **Next Steps** for the various bodies or ‘stakeholders’ responsible for the care and protection of older people. These are designed to encourage progress on the main issues highlighted by the PANICOA evidence and have been informed by discussion with relevant experts in the field, including representatives of residents/patients and from the original research teams.

THE PANICOA 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.

National care regulators continued...

- 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.
- 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.

National health and care bodies continued...

- 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).

THE PANICOA OUTPUTS

The individual studies in the PANICOA Portfolio have all provided a standard summary of the research undertaken and its main findings. These are provided in the Annexe of the full **PANICOA Report**. The studies have also, between them, produced a wide range of useful tools, advice and guidance to assist both research and practice in the field. These include:

- Dimensions of Potential Mistreatment in Institutional Care (Dixon et al., 2009);
- Guidance for Survey Research in Care Homes (Dixon et al., 2009);
- Safeguarding Policy and Law - A Policy Timeline (Manthorpe, 2013);
- Guidance and Standards Relevant to Mistreatment (the PANICOA Report, 2013);
- An Observational Tool to identify risk and preventative factors for people with advanced dementia (PIECE-dem) (Brooker et al., 2011);
- 'Inside Out of Mind' - a Playlet illuminating the experience of dementia care in hospital wards (Schneider et al., 2010);
- An Evidence-based Training Package for Care Homes (Tadd et al., 2011).

THE PANICOA STUDIES

Report date	Author & Title	Abstract	Method
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
	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 and academic literature
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 8 assessment wards
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 7 care home sites
	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 7 trial sites
2013	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 8 care home sites

Report date	Author & Title	Abstract	Method
2013 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
	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 16 acute wards in 4 hospital sites (2 for older adults and 2 for adults of all ages)
	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 and protection of vulnerable adults	individual/group interviews, surveys and non-participant observation in 8 care home sites; piloting of training package in 7 sites
	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 12 case study sites
	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 9 hospital wards in 3 Trusts

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2. The PANICOA *Main Report* can be found at: www.panicoa.org.uk
3. 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. (www.britannica.com)
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