NICE Collaborating Centre for Social Care

Transitions between health and social care guidance stakeholder scoping workshop notes

Break-out group discussions

Six facilitated break-out groups discussed specific aspects of the draft scope. The following themes emerged.

Definitions and language

Several of the groups questioned the definition of transitions presented in the draft scope and suggested the exact focus of the guidance was not yet clear. Many stakeholders challenged the use of the word ‘transfer’ since it suggested that moves between health and social care settings are single events. One group’s main point to feed back to the workshop was that ‘transitions’ involve multiple movements, can be continuous, in parallel; transitions should be understood as a process rather than a point in time or with transitions only happening in one direction. The word ‘interface’ was suggested by some groups as a better alternative and the NCCSC were encouraged to also consider ‘continuing care’ in both sectors.

Several groups suggested that the emphasis in the draft scope appeared to be on moves between hospital and social care, particularly in relation to the draft review questions. While some stakeholders suggested broadening the focus to transitions in other health and social care settings, several groups recommended that looking at moves between hospital and social care settings would give the guidance a more specific focus, and would be an area in which the guidance could make a real difference. Other groups suggested that if this was the focus, this should be made explicit.

Other points made in the groups related to the terms defined in the scope. One group suggested that a glossary should be provided with the guidance. These other points included:

- **Definition of unpaid care:** (referred to in a draft review question) – it was queried whether this related to care by family and friends or whether it could also apply to unpaid care by volunteers. Many stakeholders supported this broader definition.

- **Definition of self-directed support:** (as mentioned under key activities) some stakeholders requested that this should have a more detailed definition and suggested that some interventions could be covered by this term, such as speech and language, and dietetics. One group were concerned that ‘self-directed’ implied that neither the health sector nor social care sector have responsibility for an individual’s care when this is not the case.
- **Language used in outcomes section:** several groups suggested that criteria for success needed to be included in describing outcomes e.g. ‘Improved’ user and carer experience or ‘reduced’ social isolation. One group recommended that the outcome relating to social isolation should be rewritten with a more positive focus- to look at increased social engagement. Another group suggested that this section was not written with a service user in mind and that the language should reflect the person-centred care we should be aiming for and the goals that a service user may be aiming for (as focused on within recovery tools in mental health). Finally, there was a caution against viewing some outcomes as more negative than others. With a person-centred focus, a move to residential care or nursing care can be understood as appropriate and right for an individual.

Other terms queried included ‘impact’ (used in the draft review questions); ‘social care quality of life’ ; ‘acute’ mental health setting and there was slight concern about the consistency of using terms such as patient, service user and client. One group suggested that ‘telecare’ should perhaps be changed to ‘telehealth’ or ‘technologies’. Another group called for disabilities to be broken down as a category into physical, learning and sensory.

Finally, one group questioned what was meant when under excluded settings it cites ‘Settings in which neither health nor social care is provided.’ They queried why it was necessary to state this.

Care Co-ordination

Unsurprisingly many of the overlapping discussions from across the groups can be understood as referring to how care is coordinated across the two sectors. The following particular areas of discussion emerged:

Integration

A point raised by several groups is that by the time the guidance is published integration will be a key focus and separating health and social care in this way may be at odds with this new vision for how care and support should be organised. There were many representatives from organisations where health and social care colleagues are working together in various organising frameworks. A key question raised was how the guidance will be defining ‘integrated’. The groups asked the NCCSC and NICE to consider how this guidance will fit into this ‘new world’. There was a call from several stakeholders for the guidance to extend its remit to domains currently not covered, such as finance and housing in order to reflect this integrated approach. The importance of holistic assessment of needs was mentioned by all stakeholder groups, as was the importance of taking a practical approach. For example, one stakeholder highlighted that when assessing the technology or equipment needs of patients being discharged from hospital, it should be considered whether the equipment will fit in a bedroom. Others highlighted the need to consider the appropriateness of accommodation to which people are moving after hospital discharge. Some stakeholders suggested hospital staff need to view patients as whole people rather than through the lens of the injury, condition or illness (or combination of them) which has led to their hospital stay. Others suggested that holistic assessment is key in preventing readmissions to hospital.

Practicalities of joint working

Many of the areas highlighted by stakeholders as requiring change related to the practicalities of joint working or the lack of it currently seen in practice. All stakeholders said that an optimum transition will be ‘seamless’ and not appear to involve great change at all - with the individual at the centre, this should be every professional’s objective. Several groups emphasised the importance of timeliness- not necessarily working to imposed target deadlines but ensuring that the right things happen at the right time, with planning beginning well in advance involving all partners, including service users and their families. The time of day was particularly highlighted as a factor which appears to affect the quality of hospital discharge processes. One group questioned whether certain features of the system, such as incentives in service level agreements, actually seem to build delay into the process. Many stakeholders suggested that there should be a lead professional or care co-ordinator who is responsible for ensuring that these transitions are smooth, providing a central point of contact for individuals and their families (stakeholders queried whether the model of assigning individual GPs to people over-75 should be extended to those aged under 75, for example). This is current best practice in certain children’s services and mental health services. One group called for coordination to be included in the line on assessment in the draft scope.

Communication was highlighted as a key area of concern. Information sharing between services was the prime target for criticism – with stakeholders suggesting that computer systems and professionals have to find a way to work together in order for individuals to have good care and be able to move successfully between health and social care. Individuals should not have to repeat their story more than once – their notes should be shared, rather than duplicated so that professionals can most effectively understand the needs of people with whom they are working. One group questioned whether the guidance could recommend that care planning and assessment tools should be developed that work across services. Particular relationships such as those between GPs and care homes and care homes and hospitals were ones that stakeholders felt needed to be improved, especially when nursing or care home staff are deciding whether a resident should be admitted to hospital. The communication between hospitals and GPs was also raised as a concern, for example, delays in notifying GPs about their patients’ hospital discharge.

The issue of differences in communication styles and terminology was also mentioned by several stakeholders who called on all people involved in delivering care to seek to find common terminology and communication styles to improve joint working. (A point was made about doctors and nurses communicating differently).

Funding

The issue of funding was discussed by several groups with one group specifically looking at the Integration Transformation Fund, whereby a single pooled budget will be invested in 2015/16 by local areas in integrated health and social care services. Several other stakeholders pointed towards pooled budgets as a way of providing better care as currently the funding models of the two sectors are not particularly compatible, which is often a major cause of delays in hospital discharge. It was acknowledged this is a real challenge for everyone working across the two sectors currently and particularly for commissioners. Several stakeholders were representatives of organisations which are currently involved with joint commissioning between community GPs and the local authority which may avoid these problems. However it will be necessary to make savings in order for more money to be invested in the ITF- several stakeholders pointed towards putting homecare packages in place as a real way of saving money and reducing the number of readmissions to hospital, so there are clear overlaps with other pieces of NICE guidance.

Other discussions relating to funding focused on the importance of personal budgets and personal health budgets (particularly for increasing choice and control for service users). Participants also highlighted that even if self-funders organise their own services, they may still require help, through the provision of information, expertise and emotional support. .

Training and workforce development

The groups highlighted the need for training of the workforce in a number of areas, such as good communication, mentioned above. One group placed the impetus upon the educational institutions where professionals start their training to prepare them for working with other professionals and the skills that are needed for successful joint working. More specifically, several stakeholders suggested that practitioners in community settings (not simply care homes) should be trained to identify urinary tract infections and respiratory infections, the main causes of inappropriate hospital admissions. One group suggested that doctors and nurses should be trained in proper discharge policy, with a mapped stepping down process advising professionals about how they should be organising hospital discharge for people with particular needs. Lastly stakeholders touched on the importance of skill sharing and conducting regular review of skills and knowledge - using higher education institutions to support staff skill and knowledge ‘MOTs’.

Active communities, empowerment and citizenship

Several groups linked their comments on integration and person-centred care to the need for active citizenship and engagement within communities, to mobilise support for those who need it. The role of the voluntary sector in this and the importance of these organisations in providing care and support were championed by all stakeholder groups. Enabling and empowering people to organise their own care and set their own priorities was considered important by all groups although at the same time it was emphasised that people will always need information and support. One group suggested that with personal budgets and direct payments people need training on how to be an employer so there is a role for practitioners in educating the people they support. Other important educational or training needs for service users are medicines management and falls prevention.

As well as the two overarching themes of language and care co-ordination there were comments that related to particular topics in the scope that stakeholders wanted to challenge or draw more attention to: mental health; housing; medicines management and carers.

Mental health

Several stakeholders and one discussion group in particular challenged the exclusion of transitions between inpatient (described in the draft scope as acute) and community mental health settings. This followed on from a question asked during the morning plenary. People argued that the exclusion was not well-explained in the draft scope and required clarification. Their main argument was one calling for parity and suggesting that this exclusion would disadvantage mental health service users. They argued that NICE is a recognised national brand whose guidance would be of benefit to mental health service users and questioned what other guidance was available that meant that exclusion was justified. One stakeholder suggested that moves between general health and social care settings was not the biggest problem faced by mental health service users and therefore the guidance would not be meeting their needs. There was disagreement among stakeholders on this point - another group highlighted a recent report on the physical health problems of mental health service users and the problems of diagnostic shadowing in hospitals. Finally stakeholders argued that there was a wide range of good practice and learning from mental health that will be missed by making this exclusion, in particular relating to integrated working among community mental health teams.

Other more general comments relating to mental health included that the emotional impact of transitions on individuals **and** their carers should be considered.

Housing/accommodation

Following a point raised in the plenary session, several groups queried why the guidance will not be considering the role of housing in ensuring successful transitions. Although it was explained that making recommendations about the quality of housing was outside the remit of NICE, stakeholders argued that integrated and person-centred care should look at all elements of need, which should include housing needs, One group discussed the fact that unless social care professionals consider the quality of the housing into which a person is moving, then they are resolving one issue only to let another develop. A representative from an organisation working with stroke survivors highlighted examples of bad practice where the choice of accommodation following discharge has had a negative impact on individuals' recovery. This chimed with other groups who emphasised the need for successful transitions to ensure a move into an appropriate setting that would meet an individual's needs. This was seen as being particularly important to avoid hospital readmissions. The issue of moving people back to a situation of domestic violence was raised by one group as a concern.

Other comments relating to housing related to how 'people's own homes' are conceptualised in the scope. Several stakeholders highlighted that there a range of options which could be covered by this term which appeared to be missing from the scope such as supported living, more temporary or interim arrangements or more specialist housing settings. One group suggested the text should be altered to 'into their own home/whichever setting they are moving to', while another suggested it could be referred to as 'accommodation' rather than 'housing'. Furthermore it was emphasised that the distinction should be made between interim and intermediate accommodation. Finally the focus on residential care in review question 4.5.4 was particularly queried for excluding other accommodation settings.

Medicine management

A couple of groups highlighted the role of medicine management in supporting successful transitions between, in particular, hospital and social care settings. It was suggested this could be covered in the section on "Assessment procedures and tools".

One stakeholder was particularly concerned about the lack of training provided to family carers on the side effects of particular medicines and the effects of mixing them with off-the-shelf remedies. Another issue is whether the use of medicines by people living alone can be assured or monitored. It was suggested that this a real training need for doctors and in other health settings than hospitals, in communicating effectively how particular medicines should be administered and managed. As with other guidance, stakeholders highlighted the confusion over where responsibility lies for medicine management and other health-related care tasks delivered in the home, for example, between nurses and social care staff. One group recommended that a lead professional should be available for carers to consult with on this issue.

Carers

There were several comments made by stakeholders relating to carers:

- That the scope needs to make it clearer that support needs of carers is in scope (this will be embedded by legislation).

- Carers's needs are currently not being assessed in all settings – one example given was that there is variable practice in involving carers in discharge planning in hospitals.
- Several groups recommended that young carers under the age of 18 should be considered, despite the all-adult (aged 18 years and over) population focus.

- Finally, stakeholders emphasised that a carer's wellbeing should be included as an outcome.

Technical aspects of the scope were also discussed by the groups - the population; review questions; evidence base; audience and composition of the Guidance Development Group.

Population

All groups were happy with the all-adult population focus. There was more diversity of opinion on the potential sub-groups of interest. Several groups highlighted other sub-groups that might be of interest:

- People with learning disabilities
- People with mental health conditions
- Homeless people and those with unstable housing (e.g. living in hostels)
- People on the autistic spectrum
- Refugees and asylum seekers
- People living in isolation
- Family carers
- Young carers (under 18 years)
- People in socially deprived areas
- Black and minority ethnic groups
- People with long term conditions and/or co-morbidities
- People with rare conditions
- Those with no recourse to public funds
- People who don't approach care and support services for help
- Those receiving end of life care
- Gypsies and travellers.

In contrast many other stakeholders argued that looking at sub-groups was unhelpful and that the guidance should instead provide general principles that can be applied to all. People argued that no one group was more important than another. One group argued that people with particular needs should only be considered if the evidence suggests they are particularly vulnerable or discriminated against. Consequently they recommended a review question should be added that looks at this issue in particular.

Review questions

Many groups were happy that the review questions covered most of the important issues. As mentioned groups requested clarification on terms used in the questions and suggested that vulnerable groups should only be focused on if, due to a review question, evidence was found to support this. Other comments on altering questions included:

- Which health problems (the example given was sensory impairment) are overlooked during problems of delayed discharge?
- Try and focus more on the move from social care settings to health care in the review questions e.g. ‘What are the experiences of service users who transition from social care support to health?’
- Several groups recommended that evidence on the views and experiences of professionals involved in care across the sectors should be sought as well as those of service users and their families.
- Residential care, nursing care and supported living should all be covered (a reference to question 4.5.4 in the main).
- 4.5.3 was considered by one group to be too broad a question to be included.
- One group queried if 4.5.4 strayed into ‘prevention’ which, they were concerned would make the scope too broad. In contrast, another group suggested it would be good to look for evidence on this issue. They cited the the figure of 5.3 million unplanned admissions and suggested that many people attend A&E because their GPs fail to provide suitable care, or appointments are not available. The group felt that if there is evidence about how to prevent unnecessary admissions or readmissions, the guidance could make a big difference by focussing on this.
- Other suggested topics for review questions included: the role played by resources or funding in how successful transitions are; end of life care and the training gaps of the workforce.

Evidence base

Several groups made comments on the possible evidence base for this guidance and what kind of evidence that the NCCSC should be considering. One group called for a broader range of evidence, not just randomised-controlled trials to be considered in order to capture social care learning more extensively. Literature on personal experience was considered very important by stakeholders. Several groups pointed to the voluntary sector as a good source of evidence on this guidance topic, alongside reports from think-tanks such as King's Fund, Nuffield or NESTA. Benchmarking evidence about different types of care provider was suggested as important by one group. One group, re-emphasising the evidence available within the mental health sector, pointed to social evaluations of programmes whereby acute, community and older people's mental health services are delivered by the same organisation. One group suggested that there was a lot of good practice evidence from Scotland on integrated and innovative practice, whilst also suggesting other particular evidence of interest, such as research on applying FACS criteria consistently, and the report arising from the Parkinson's UK APPG on continuing care in the NHS. Finally there was the suggestion to look for international examples.

Audience

There were diverse opinions on the potential audiences for the guidance.

- One group felt strongly that commissioners from across health and social (CCGs, Health and Wellbeing Boards, local authorities) should be targeted, a view that several other groups endorsed.
- Frontline staff (and their managers), also referred to by stakeholders as practitioners, who are conducting assessments and delivering care were highlighted as another key audience. A wide variety of professions were mentioned in this context, including: social workers; nurses (hospital and community); GPs; discharge teams; occupational therapists; care management teams; intermediate care teams; community health teams and many others.
- Several groups felt than an important audience for the guidance would be the general public who may use these services or be supporting people who do. One group envisaged that this guidance could be used by people to advocate for good care.
- Other potential audiences suggested were:
    - CQC
    - Healthwatch
    - Voluntary organisations focusing on social care
    - Patient transport services
    - Care providers
    - PALS
    - Housing organisations

  - Education
  - Professional bodies , training bodies and educational institutions

Guidance Development Group composition

The range of suggestions for audiences was also reflected in the discussions on representatives who should feature in the GDG for this guidance topic. Suggestions included:

- Those who have experience of good joint integrated services
- Integration pioneers
- Allied health professionals
- Doctors – community geriatrician, psychiatrist, GPs/ primary health
- Nurses- community and hospital
- Ward clerks
- Discharge coordinators/team representatives
- Social care practitioners
- People with a range of experience e.g. carers who are also health and social care professionals, or people who have worked in different sectors.
- Social enterprises
- Professionals with an assessment background
- Service users and/or their carers
- Older people/ people with long term conditions or disabilities
- People with learning disabilities or who work with those with learning disabilities
- Representatives from the voluntary/community sector- e.g. Sense; Deaf-Blind UK; Action on Hearing Loss; MIND; Neurological Alliance
- Those producing strong work on preventative side – RVS or Age UK
- Local Authority commissioners
- Healthwatch
- Providers – voluntary and private
- Urban and rural health or social care representatives
- Care home workers
- Representatives from educational institutions
- Financial advisers/insurers for self-funded care, moving from funded to self-funded
- Specialised health services
- Continuing health care (funding) representative
- Academic specialising in this area with research expertise

Other issues raised

Finally, the following other issues were raised:

- Transport was raised by several groups as important, particularly ambulance services, and this should be included as an activity.

- It was questioned whether or not alcohol/drug addiction services would be included.

- Make sure that occupational therapy is listed as an intervention

- The scope should place more emphasis on funding – who funds what, hospital/social care. As more people are funding their own care and becoming consumers of care, the guidance should be developed from their perspective and written in their terms.

- There was feedback on other particular aspects of current practice - that ophthalmologists need to provide more clarity in their reports; that the Personal Independence Payment, introduced by the DWP to replace Disability Living Allowance, requires more thinking in order to prevent disabled people falling through the net and missing out on vital support; that local authorities are good at supporting the set up of direct payments but not good at sustaining support to those using this system.

- One group discussed risk stratification tools in detail and the role they play in anticipating hospital readmissions. The PRAM framework for risk assessment was recommended as a good tool.