



National Voices

People shaping health
and social care

National Voices

Principles for Integrated Care

The lack of joined-up care is the biggest frustration for patients, service users and carers. Conversely, achieving integrated care would be the biggest contribution the health and care services could make to improving quality and safety.

Patients, service users and carers want continuity of care, smooth transitions between care settings, and services that are responsive to all their needs together.

The Health and Social Care Bill 2011 will give the key commissioning and regulatory organisations in England duties to secure or promote integrated services. We, as organisations representing the interests of patients, service users and carers, want integrated care to develop quickly and at scale.

A range of different approaches should be developed and tested. There can be no single definition, model or system. However, there is a need for common principles to inform all the approaches – principles which put patients and service users at the heart of care.

We are asking the relevant Secretaries of State, all commissioners, regulators and relevant professional organisations to give explicit support to these principles.

Based on the experiences of service users, and research evidence, we state that integrated care must:

- be organised around the needs of individuals (person-centred)
- focus always on the goal of benefiting service users
- be evaluated by its outcomes, especially those which service users themselves report
- include community and voluntary sector contributions
- be fully inclusive of all communities in the locality
- be designed together with the users of services and their carers
- deliver a new deal for people with long term conditions
- respond to carers as well as the people they are caring for
- be driven forwards by the commissioners
- be encouraged through incentives
- aim to achieve public and social value, not just to save money
- last over time and be allowed to experiment

1. Describing success – what would patients say?

Before considering the principles in further detail, it is worth establishing what success might look like from the perspective of people who use services.

Below are some of the kinds of statements patients and service users could make, if care services were better joined up:

There were no big gaps between seeing the doctor, going for tests and getting the results.

I was always kept informed about what the next steps would be.

I was told about what other services were available to someone in my circumstances, including local and national support organisations.

The professionals involved with me talked to each other. I could see that they worked as a team.

I always knew who was the main person in charge of my care.

I had one first point of contact – a person who understood both me and my condition -- who I could go to with questions.

That person helped me to get other services and help, and to put everything together.

I could see my health and care records at any time to check what was going on. I could decide who to share them with. I could correct any mistakes in the information.

Information was given to me at the right times. The information was comprehensive: it was not just medical, but also helped me understand the impact of my health status on other parts of my life.

Information included how to manage financially.

I was not left alone to make sense of information. I could meet a professional when I needed to ask more questions or discuss the options.

I was as involved in discussions and decisions about my care and treatment as I wanted to be.

My family or carer was also involved in these decisions as much as I wanted them to be.

I worked with my main professionals to agree a care plan.

I know what is in my care plan. I know what to do if things change or go wrong.

Those plans were clearly entered on my record and respected by each service I used.

When something was planned and agreed to, it happened without me having to chase around for it.

I had regular reviews of my care and treatment, and of my care plan. I was as involved in these as I wanted to be. And my family or carer was involved as much as I wanted them to be.

I was involved in decisions about my medicines – whether they were needed, and which one to use.

If I needed a new medicine, its purpose, potential side effects and how to take it were explained to me.

I was offered the opportunity to become more educated about how to manage my own symptoms. This helped me to set goals, and include them in my plans together with my main professionals.

When I was discharged from a service, there was a plan in place for what happened next. This was delivered without unnecessary delays.

If I moved from one care setting to another:

- I knew in advance where I was going, what I would be provided with, and who would be my main point of professional contact
- I was given information about any medicines I was taking with me – their purpose, how to take them, potential side effects
- Information about me, including my views and preferences and any agreed care plan, was passed on in advance
- I was still allowed to see and work with, as appropriate, preferred professionals who I already knew and knew me

When I went to a new service, they knew who I was, what my circumstances were, and about my own views and preferences, and any care plans I had made.

If I moved across geographical boundaries I did not lose entitlements to care.

When I needed support to live at home, services worked together to provide it. I had a say in who would come and provide my care and when.

When I needed special equipment to live at home, it arrived in good time.

When my professionals knew there was a risk of emergencies happening, they:

- put measures in place to prevent that
- ensured I was regularly contacted to check on me
- gave me ways to sound an immediate alert if I was at risk

If I needed residential care, I had a choice of provision so that I could find one to meet my particular needs.

My residential care provider maintained close links with the health and social care professionals I already knew outside, and enabled me to see them when necessary.

My full health needs were still provided for in residential care. My GP stayed actively involved in my care.

Measures of success

There are various well researched and tested measures that build on some of the types of statement listed above in order to produce systematic indicators of success.

Surveys and research with patients, service users and carers have focused on measures of activation, outcome and experience:

Patient Activation Measure

The PAM is a set of questions to measure the extent to which patients are active in (and confident about) managing their own condition and healthcare.

Patient Reported Outcome Measures

PROMs describe outcomes in terms that are relevant to patients' lives and on which they can report, such as a reduction in pain or an increase in mobility. There are generic PROMs including some for long term conditions, as well as specific measures suited to specific treatments.

Patient Experience Measures

Patients can report on their experiences of using healthcare services through a wide variety of survey instruments. The best tested and developed measures are those used in the Department of Health's national patient survey programme, run by the Care Quality Commission.

All these measures have potential relevance and application to measuring and monitoring the success of integrated care.

However, in general these measures have been designed and developed for use in relation to single episodes of care, usually in specific care settings, such as a consultation with a GP, or following a surgical treatment in hospital.

It should be an urgent priority for the Department of Health to invest in their further development and use in relation to integrated care – that is, in a context where people are going on 'care journeys' across and between services, and lasting over time.

2. Background

In May 2011 National Voices published its '9 big shouts' calling for improvements to the government's proposed reforms of the NHS.

The top demand, based on consultations with our member charities, was for 'integration, integration, integration'. We stated that:

"Patients and service users want services that are organised around, and responsive to, our human needs. We are sick of falling through gaps. We are tired of organisational barriers and boundaries that delay or prevent our access to care. We do not accept being discharged from a service into a void.

"We want services to be seamless and care to be continuous.

"That means primary and community health services, social care services, and services from voluntary organisations should all mesh together to help us succeed in managing our lives and conditions."

The call for integrated care was echoed by many other professional and NHS organisations, and strongly reflected in the final report of the NHS Future Forum.

In response, the government made a series of amendments to its Health and Social Care Bill to give the new commissioners, the Health and Well-being Boards, and the regulator, Monitor, similar duties to promote or secure integrated care where this would raise the quality of services for their users.

But there is a lack of consensus on what should constitute integrated care, which sectors should be included, and how it should happen.

National Voices is particularly concerned that any new drive towards integrating care should:

- always be focused on the needs of, and outcomes for, the people who use services, and
- not exclude the crucial contributions made by the Third Sector.

This document represents our first contribution to what will be a continuing dialogue across the health, social care and voluntary sectors.

Our starting point is the understanding, expressed by our member organisation, Diabetes UK, in 2010, that, among the 'key drivers' for integration, it should be accepted that:

*"there is no single correct way to integrate care.. [but] There are generic principles that can be used to stimulate change and measure progress."*¹

¹ 'Integrated Care for the Person with Diabetes: a report from the Diabetes UK Integrated Care Task and Finish Group', May 2010

3. The principles explained

The principles we propose fall into two groups – those which bear on the *nature* of the care to be commissioned, and those which address the *organisation* of integrated care.

The nature of integrated care

- **organised around the needs of individuals (person-centred)**

Patients, service users and carers want person-centred care that responds to personal needs; enables them to understand their health status and their care and treatment options; involves people in decisions; enables them to remain independent and in control whenever possible; and takes account of the needs of families and carers.

‘Integration’ which only brings systems and structures together, without making the services more responsive to their users, is a wasted opportunity. ‘Integrated care’ doesn’t qualify as such unless the services integrate at the point of the consumer.

Commissioners will be under a duty in the Health and Social Care Bill to ensure that ‘each patient’ can be fully involved in the care and treatment they receive. There is also a duty on patient choice which is intended to include choices about care and treatment.

We refer to the definition of patient-centred care used by the World Health Organisation, which states that:

“people have the right and duty to participate in making decisions about their health care, and not only in issues of treatment and management, but for broader issues of health care planning and implementation”²

We use the term ‘person-centred’ in order to recognise that a) integrated care should meet the needs of people who may not continuously be NHS patients, and b) services are likely to be better for their users if the people who deliver them (staff) are also cared for.

- **focus always on the goal of benefiting service users**

Evidence shows that many experiments in pooling budgets or joining up organisations have not resulted in tangible benefits to service users. This is because they did not set goals that focused on patient benefit, and therefore were not clear from the start what would be achieved, from the service user’s perspective.³ Often that was because they instead were aiming on benefits to organisations, such as saving money through pooling budgets or back office services.

Organisations including the Audit Commission, the Nuffield Trust, and the Integrated Care Network of the NHS have recommended that integrated care should always focus on the benefits to be achieved for patients, service users and carers.^{4 5 6}

² ‘What is people-centred healthcare?’, World Health Organisation, Western Pacific Region, People at the Centre of Care Initiative, 2006; http://www.wpro.who.int/sites/pci/health_care.htm

³ ‘Means to an end Joint financing across health and social care’, Health national report, Audit Commission, 2009

⁴ *ibid*

⁵ ‘Only Connect: policy options for integrating health and social care’, Professor Chris Ham, Nuffield Trust, London, 2009

⁶ ‘A practical guide to integrated working’, Integrated Care Network, London, (undated)

- **be evaluated by its outcomes, especially those which service users themselves report**

This principle states first, that integrated care experiments should be evaluated. A great deal more learning is required in order to spread good practice and ‘scale up’ success. Commissioners need to build this in from the start – ie to consider setting up evaluation processes *as part of the package of commissioning*.

Second, if integrated care is ‘goal-oriented’, then evaluations must focus on whether the stated outcomes are achieved.

Third, outcomes will be a mix of clinical outcomes (is the care more or less effective than in alternative or preceding services?), and patient-reported measures. Only patients, service users and carers are in a position to report whether the service was better from their point of view, in terms of experience.

We note that, while some tried and tested patient experience measures are available, there is an urgent need to develop ways to measure and monitor patient experience over time, along care pathways and across different services, rather than in specific episodes.

- **include community and voluntary sector contributions**

Voluntary and community sector organisations make significant contributions to the care and treatment that people choose to make use of. This sector is particularly good at:

- spotting gaps in provision, and finding innovative ways to fill them
- identifying discontinuity between services, and working to bridge it
- seeing the patient or service user as a whole person, and working to meet their needs in the round.

The role of the sector in provision is important. Patients, service users and carers who are in receipt of large volumes of care and treatment often express the view that they ‘could not have coped’ if it were not for the small but pivotal contributions made by the helplines, information provision, care advisers, peer support groups, or specialist nurses that the Third Sector has organised.

However, statutory services are often ignorant of these contributions, do not see them as a commissioning priority, or marginalise them from the consideration of which services should be joined up.

The sector’s role is multi-layered. It is not only, as policy makers and commissioners seem to assume, ‘competing for provision’. Its contributions also include:

- identifying and assessing need, especially among under-represented or seldom heard groups
- engaging patient, service users and carer voices to provide insights to commissioners and providers
- co-designing services with commissioners and with end users
- advocating for changes to service patterns and care pathways and challenging vested interests when necessary.

We argue that the voluntary and community sector should therefore be seen as the ‘third circle’ in the Venn diagram of integrated services, overlapping with healthcare and social care.

There is almost always a role or potential role for voluntary and community sector input, and commissioners should therefore always be making an assessment of what that input could or should be.

- **be fully inclusive of all communities in the locality**

Meeting the needs of the small population of people with the most complex health needs remains a considerable challenge. People from minority and socially excluded groups experience poor health outcomes across a range of indicators including self-reported health, life expectancy and morbidity.

The groups referred to here include parts of the Black and minority ethnic population, and excluded groups such as homeless people, travellers, sex workers, and people addicted to narcotics.

The desired outcomes that are set for integrated care must include locally appropriate specific targets for equality of service and of outcomes for people who often are not included in health and social care planning. They tend to make more use of unplanned services such as urgent care.

Commissioners will need to design integrated care services that are socially and culturally competent to provide appropriate access for excluded groups both to mainstream services and to the specialist socio-medical services they may also require.

Using the above principle of recognising the contribution of the community and voluntary sectors, commissioners may need to mobilise organisations and groups in these sectors to help identify and assess the needs of minority and excluded groups in their area.

Equality indicators will be required that can measure this competence and assess whether such groups are getting the access and the outcomes that other groups in society are achieving.

- **be designed together with the users of services and their carers**

Opportunity costs can be avoided, and the value of care increased where the design of care involves end users from start to finish as equal voices.

Especially in relation to chronic conditions, service users become knowledgeable, over time, both about their condition and about what works best to enable them to treat it and live with it.

All parts of the system therefore have an interest in developing 'co-design' in commissioning, which should be prioritised under commissioners' duty to involve the public in commissioning arrangements.

- **deliver a new deal for people with long term conditions**

The consensus is that the biggest challenge facing health and social care is the continuing rise in the number and proportion of people with one or more long term conditions who, for example, consume 70% of healthcare spend.

Since people with long term conditions consume more services, over a longer period, and since current models of care based on episodic patterns of usage are clearly unsuitable to the challenge, it is in this area that integrated care offers the greatest potential both to improve quality and to provide a better experience to users.

In its submission to the NHS Future Forum in May 2011 National Voices called for a 'new deal' for people with long term conditions, which would include:

- access to their electronic health records
- a jointly prepared and annually reviewed care plan
- a designated care co-ordinator able to deliver agreed packages of care
- support for self-management, and
- support to navigate the system.

Evidence shows these interventions are effective in improving patient knowledge and confidence to manage their condition and their care; and improving the use of care system resources.⁷

- **respond to carers as well as the people they are caring for**

Most people with multiple care needs will have a main carer (most often a spouse or family member) looking after them. These carers not only provide the bulk of people's care, but are the principal players in trying to organise appropriate packages of services.

Integrated care services need to be designed to work with carers as full partners, and to respond to their needs with the same compassion and professional respect that they show to patients themselves.

Carers should not be shut out of consultations, refused information or ignored when they ask questions. They should be part of the team working with the patient on key discussions and decisions.

Carers' first priority will be to get the right care and treatment for the person they are caring for. But managers and professionals in integrated care need also to recognise that assessing carers' needs and ensuring they are supported is a vital underpinning to the success of care overall.

⁷ www.investinengagement.info

The organisation of integrated care

- **be driven forwards by the commissioners**

When the Nuffield Trust searched for innovative examples of integrated care from the last two years, they found that most of these had been initiated by providers, rather than commissioners.⁸

We are in favour of care providers initiating innovation. However, there is a general risk that provider-led initiatives may result in service redesign that meets the interests of the specific provider(s), rather than being focused on benefits to patients, service users and carers.

There is a particular risk that large, dominant NHS acute trusts will be able further to monopolise control of resources in the local care economy. This may result in resistance to relocating care and treatment, for example to bring it closer to people's homes and communities; whereas National Voices has repeatedly called for care to be delivered 'in the right place, at the right time', and at community level wherever that is most appropriate.

In order to mitigate this risk it is vital that commissioners commission. They should lead collaborative approaches across the local care economy, involving all sectors including relevant professionals and managers in the acute sector, and including the voluntary and community sector. But they must also be prepared to challenge current patterns of care where that is in the interests of the users.

In making such challenges, commissioners are most likely to succeed where they have the support of patients, service users and carers themselves, for example by involving them as key stakeholders in the redesign.

- **be encouraged through incentives**

Redesigning care and treatment around the needs of people and communities will involve considerable change and the breaking down of current barriers.

Recently, partly for historical reasons (such as continual structural change) and partly because of the context of retrenchment and efficiencies, there has been a tendency for services to 'reduce and withdraw' rather than to pull closer together.

Government, commissioners, regulators and professionals should move swiftly to agree on fair frameworks of incentives that will reward people for 'doing the right thing' in establishing integrated care.

Current payment systems within the NHS reward 'lots of activity'. The government has signalled that, instead, it wants to reward outcomes. Much attention is focused on the necessary task of redesigning the 'tariff' that commissioners will pay for their population's services.

However, many of the services people use are not subject to a tariff. Mental health and musculoskeletal services are obvious examples.

Furthermore, it currently takes five years to gather data and design a tariff – a pace which is too slow both to meet the challenges of rising consumption and to satisfy patients who are already frustrated with the lack of joined-up services.

⁸ 'Commissioning Integrated Care in a Liberated NHS', Ham C, Smith J and Eastmure E, Nuffield Trust, 2011

The question of incentives should therefore be dealt with 'in the round'.

Other categories of incentives need to be considered simultaneously.

These could include performance incentives to commissioners based on achieving outcomes through integrated care; professional incentives such as enhanced professional development to support new care patterns; and incentives relating to improved working lives and professional satisfaction, for example where professionals are freed to spend more time directly with patients and service users in the new services.

At a system level, all current systems of incentives such as QOF, CQUIN, and standard contract incentives should be reviewed to see how they can best support and reward integration.

- **aim to achieve public and social value, not just to save money**

Integrated care is expected to bring efficiencies and potential savings.^{9 10} However, if 'cost saving' becomes the main driver, it will undermine the achievement of other goals related to person-centred care and better outcomes for patients and service users.

The aim should not be to 'save money' but to **achieve public and social value**.^{11 12}

That is, it should encompass¹³:

- a) *quality* -- providing better care and treatment, with better outcomes and experience for the users
- b) *cost-effectiveness* – making best use of limited resources, which may include greater uptake of some services such as screening and prevention
- c) *reach* -- not just treating those who come through the door, but ensuring all community needs are met
- d) *impact* -- producing wider benefits to the public and communities such as, for instance, developing more health literate, self-caring and health-preventive communities

'Public value', in most formulations of the concept, includes operating through the approach of 'co-production' – value is produced by the public service acting in partnership with its users – and emphasises the role of service managers and commissioners as innovators on behalf of citizens.

⁹ 'Removing the policy barriers to integrated care in England', Ham C and Smith J, Nuffield Trust, London, 2010

¹⁰ 'Benefits Realisation: Assessing the evidence for the cost benefit and cost effectiveness of integrated health and social care', Turning Point, London, 2010

¹¹ Professor John Benington defines public value as incorporating first, what the public values and second, what adds value to the public sphere. 'Public value' approaches are particularly apposite to socialised healthcare and are discussed at:

http://www.institute.nhs.uk/commissioning/tackling_tough_choices/an_introduction_to_public_value.html

¹² 'Social value' refers to "the wider non-financial impacts of programmes, organisations and interventions, including the wellbeing of individuals and communities, social capital and environment": 'Measuring Social Value: The Gap between Policy and Practice', Wood and Leighton, DEMOS, 2010

¹³ This definition would parallel the BBC's definition of public value during the current Charter period.

- **last over time and be allowed to experiment**

Integrated care takes time to establish, develop and improve, and to demonstrate its benefits, especially where it is attempted at scale. If integrated care is forced to demonstrate short term gains, especially in resource use, it risks failure.

Government, statutory services, regulators and collaborating professionals must together have the courage to commit for the long term – longer than is the norm in politics or in ever-changing public services.

Moreover, integrated care is a relationship business. Whatever the structures and processes of the contributing organisations, success depends on the trust, mutual commitment and collaborative goodwill of people in positions to change things.

This *relationship capital* must be protected and allowed to grow without the continual disruption of policy changes and organisational reform.

There are no templates or guaranteed models for integrated care in the English context. Pioneers of integrated care, especially those attempting to work at scale, must be given clear permissions to experiment. There will need to be a positive approach by government, service managers, local politicians, regulators and professional bodies towards removing or suspending barriers to these experiments.

Commissioners and providers alike will need to support these experiments, in particular in their approach to the workforce, including:

- giving people permission to work on the development of integrated care services, and to work across organisational boundaries in multi-disciplinary teams
- planning to retrain and reskill the provider workforce to change their organisational and professional styles of working with the people who use services.