Integrated care: what do patients, service users and carers want?

Top Lines

People want **co-ordination**. Not necessarily (organisational) integration.

People want **care**. Where it comes from is secondary.

Overview

The aspects of care correlating most closely with good patient experience are *relational.* Patients want to be listened to, to get good explanations from professionals, to have their questions answered, to share in decisions, and to be treated with empathy and compassion[i]. These aspects are found in individual consultations and in team working. But integrated care arrangements need to be crystal clear about the roles and contact that various professionals will have with service users.

People want many other things from healthcare, including continuity of care and smooth transitions[ii]. These require planning and co-ordination[iii]. They may not require organisational 'integration'. By efficiently deploying multi-professional resources, co-ordinated care systems should be better able to deliver the other things patients require: fast access, effective treatment, respect for their preferences, support for self-care, and the involvement of family and carers[iv]. Hence 'integration, integration, integration' was the top demand from patient, service user and carer organisations during the 'pause'[v].

Patients have little interest in organisational/institutional priorities or mergers. They want organisations not to argue between themselves or send conflicting messages. They expect *professionals* to work together as a 'team around the patient', and they want *services* to work together likewise: that is, to come together at the point they are needed, and to meet people's needs in the round.

People understand that there are resource limitations, and indeed are often self-limiting in the use they make of services and professionals' time. But they want to know clearly what their *entitlements* are (not just to care but to support and finance), and what *costs* they might incur, at any key point on their journey. They want services easily to agree on these and not to argue between themselves. They want obvious efficiencies to be achieved – not least in use of their own time – for example by making it possible for multiple appointments to happen on one day; or by linking diagnostics and consultations seamlessly together. They want agreed packages of care to be delivered without delay.

'Care is care is care' for the person who needs it. Divisions into 'primary', 'secondary', 'community' and 'social' care are relatively meaningless. (Note, however – care from 'social services' is still associated with stigma by many older people; NHS care is not[vi].)

The people for whom integration is most relevant, especially those with long term conditions, consistently say that they are looking for the 'system' to combine two things in one place:

- **knowledge of the patient/service user/carer as a person**, including their home circumstances, lifestyle, views and preferences, confidence to care for themselves and manage their condition(s), as well as their health status and symptoms
- **knowledge of the relevant condition(s) and all options** to treat, manage and minimise them, including knowledge of all available support services

People know they may need a variety of professionals and support services, but within this they want a *single trusted point of liaison*, to which they can have recourse as necessary, where the above knowledge is held. They expect this person/service to advise them on how to take next steps and, ideally, to co-ordinate their care or to help the patient/carer to co-ordinate it..

People tend to 'personify' this where they find something approximating it. Older people with long term conditions cite their clinical nurse specialist. Those families whose child has complex needs and who have a 'key worker' system give positive feedback.

> "You need the person with the backpack of knowledge who can walk beside you."
> Carer of spouse with Alzheimer's

Describing success – what would patients say?

Being able to set, and be judged by, patient-focused outcomes will be key to the 'next generation' of integrated care approaches. Such outcomes are not readily available. This section attempts to describe some.

Because the current health system, and the health and social care systems, in England are not well integrated, what people want is normally described negatively. For example: people do not want to fall through gaps, to be forgotten about, to have to explain themselves anew to every professional or service they encounter, and so on.

To help the development of integrated care we need to turn these statements around.

Patient experience surveys have shown we can ask neutral, objective questions that enable patients to report what was good and bad in their care. Some of these established indicators are relevant to integration[vii]:

> Were you given a choice of admission dates by the hospital? (yes/no)
> Did you feel you were involved in decisions about your discharge from hospital? (yes/yes, to some extent/no)
> (at discharge) Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you? (yes/yes, to some extent/no)

If we can take the evidence of what patients want, and express it as a series of plain statements, these can be used to derive measures of success relevant to various different care settings that people might use. The statements below have been consulted on widely with voluntary sector organisations who have agreed their relevance. (They are only a starting point and not exhaustive.)

Statements describing good integration

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.

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

Care co-ordination

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

I had one first point of contact. They understood both me and my condition. I could go to them with questions at any time.

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

Information

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 appropriate to my condition and circumstances.

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

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

The information I was given included how to manage financially.

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

Shared decisions/care planning

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.

My care plan was clearly entered on my record.

When I used a new service, my care plan was known in advance and respected.

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. My family or carer was involved as much as I wanted them to be.

Medicines/self management

I was as involved as I wanted to be in decisions about my medicines – whether they were needed, and which one to choose.

If I needed a new medicine, its purpose, potential side effects and how to take it were explained to me. I was given written information about this.

I had a key professional who helped me to manage my medicines and to check how they were working.

I had regular, comprehensive reviews of my medicines.

I was offered the opportunity to become more educated about how to manage my own symptoms. This helped me to set goals. I agreed the goals with my main professional(s).

Transitions

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.

Managing at home

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.

My carer/family had their needs looked at and were given support to care for me.

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

Residential care

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.

<u>The three exemplar groups</u>

The statements above were tested with charities working with the three exemplar groups[viii]. They agreed the statements were **useful and relevant**. They then suggested additional issues relating to their beneficiaries (see below)

<u>Children with complex needs</u>

Families use many services. These are not well linked to their local community. Defensive approaches mean they are rapidly referred into specialised services, usually far from home. Discharge from here back to home is fraught with unknowns and disagreements about continuing care packages.

(Note: similar experiences may also be reported by people with enduring mental health conditions if they become inpatients; or by patients with less common conditions who move between home and specialised centres.)

There is a specific issue for children who come up against barriers – the *developmental* impact. For example, if they cannot access education while waiting for special equipment. Children benefit developmentally from being given maximum autonomy.

There is a specific transition for children which other groups do not face – crossing the boundary from child to adult services. This process may be driven by education professionals since that is where the move takes place; but health and social care may fail to recognise this, and to 'buy in' to new care plans.

<u>Adults with enduring mental health conditions</u>

These are fluctuating conditions. Individuals' needs escalate and decline at different times. This can be sudden and unexpected. Even where it is predictable, individuals still need to be reassessed to access services. This delays timely and effective care.

Fluctuation means some people have more than 8 assessments in a year to access the different services they need for their condition. There needs to be some continuity of information and record keeping between these assessments: a) to avoid having to repeat basic information and case history, (except that information which the patient wishes to control to prevent confidentiality being breached); and b) to provide comparison with past episodes for care planning (for example, knowing what previous drug reactions have been). The care planning and assessment process needs to be continuous.

Integration needs to provide preventive approaches. Social care can be important in supporting someone to recover, or helping someone whose needs have recently increased, to prevent a crisis and hospital treatment. High eligibility criteria for accessing social care can mean this support is only provided at crisis periods. Preventable hospital admissions, which disrupt lives, may be worse for people's health than the initial crisis itself.

Later, recovery can mean services are withdrawn – leading to a 'fear' of getting better. People are discharged into primary care where the quality of mental health awareness and provision is patchy. Although their mental health needs may be dealt with, the other needs that underlie their unstable health may not be – including their physical health. Dual diagnosis patients can be excluded from services because of their addiction, and therefore go untreated. Yet, often addiction is self-medication for the mental illness.

Crisis resolution teams act as gatekeepers to inpatient care and can ensure care is provided in the home where this is appropriate. However, individuals cared for in the community can end up working with different staff or a new community psychiatrist each time. This hinders the effectiveness of treatment in mental health where the patient / clinician relationship is crucial.

Care planning approaches were pioneered in mental health but many service users still report not being fully involved in making and agreeing them[ix]. Full care planning and co-ordination is only triggered for people with 'severe' needs.

Frail elderly people

Key issues relate to whether the person may be approaching the end of life: a) when and by whom is an assessment made; b) whether the end of life pathway is properly integrated.

More than one fifth (92,000) of those who need palliative care are not being reached[x]. There is no smooth transition into end of life care because doctors are uncertain when to make an assessment, or to refer to others for assessment. Hence the frail person may continue to be treated on a 'cure and discharge' basis.

GPs lack confidence in communicating prognosis and discussing care planning with patients and families[xi], and this may be true of other professionals. But care plans need to be made, anticipating the future precipitation of end of life care, which can be unpredictable. For example, admission to residential care or discharge from hospital should be 'crunch' points to make contingency plans.

Once on end of life care, people find the pathways are not integrated, and failures here are amplified, resulting in hospital admissions, 'drop-offs' in social care support eg on discharge, and people dying in hospital. The palliative care funding review recently published recommendations for funding integrated end of life care[xii].

Care co-ordination is poorly developed and in practice done by the spouse/family/carer. There are huge risks for people who are single and lack family or social support.

Medicine prescription, use and management is a dominant issue in people's care and treatment. This is alarmingly amplified in residential care where a resident commonly takes around eight different medicines every day[xiii] and errors are made daily[xiv].

Big Issues

The person alongside the person – care co-ordinator/key worker

Co-ordination is key to joining things up for service users. **Every integrated care programme must include detailed specification of where, how and by whom the care co-ordination function will be provided** for targeted groups of patients -- or it will fail.

The *person* providing co-ordiantion may not be the same professional for every patient of a single type – patient preference and health status are significant. Historically and professionally GPs have been seen/seen themselves in this role but it needs to be **shared/delegated through team working across boundaries**.

The person alongside the person – advocates/navigators

There is strong support for advocates for people with reduced capacities to care and manage for themselves, and/or lacking in family/carer support. Especially relevant to people with enduring mental illness or learning disabilities, isolated frail elderly people and children with complex needs. Q: is the care co-ordinator also the 'advocate'? A: yes in less severe/complex cases; but **with more complex needs, advocacy needs to 'travel with' the service user** ie be alongside them at the front line of service use.

Care planning approaches – make more widespread

People who most need integrated services also would benefit from personalised care planning. Indeed care planning is a major contributor to integrating care for the individual. It is not widespread and should be more so. Care plans need regular (annual) review but should be actively reviewed and amended with the patient at all 'crunch' points -- transitions or changes in care. Access to records and portability of records would help (see below).

Care planning – understanding it, and gaining the requisite skills -- should feature large in new medical and nurse education and training curricula.

> "At present, only 10% of people with asthma in England have a written personal asthma action plan." Asthma UK[xv]

> "In 2008 only 13% of the people with epilepsy who were questioned had a care plan." Epilepsy Action[xvi]

> "despite universal recognition of their value, care plans are often absent or rudimentary." Specialised Healthcare Alliance

Medicines decisions, management and review

For groups who most need integrated care, management of medicines is a central and time-consuming issue. In all treatment settings many patients say they were prescribed new medicines without being told about the purposes, the potential side effects, or how to use them properly, and without being able to participate as much as they wanted in the choice of medication. Professionals treating patients in single episodes of care will tend to 'prescribe

and forget'. There is little local expertise in the effects of combining medicines for different conditions. **Proper, comprehensive medicines reviews need to happen as part of care planning at each 'crunch' point**, and service users enabled to play as full a part as they wish.

Pain control

Although the aspects of care that correlate most closely to the quality of experience are relational, there is an exception in some settings – pain control. Some of the groups most in need of integrated care will either be unwilling/inhibited from (eg frail elderly people) or unable (frail elderly, some mentally ill people, some children/young people, people with learning disabilities) to communicate the degree or type of pain they are experiencing. There are risks of people being passed from one service to another without the degree and nature of their pain being adequately assessed or mitigated. **Pain and its control should be recognised as an aspect of the 'dignity'** to which people are entitled[xvii].

Information

Integrated care cannot work unless information flows work[xviii].

Information *for* patients should be commissioned (not left to 'appear' or not appear through local initiatives). A priority should be to commission for the most common conditions a **clear, easy-read 'map'** for each patient of what they should receive and from whom. These should be on NICE guidelines and standards (or on the Map of Medicine) wherever possible, and commissioners should ensure they are used and promoted.

Information needs **along care pathways** should be carefully considered and commissioned from accredited providers. Information should not only be medical – it should be **holistic and comprehensive** (social, emotional, financial effects of conditions; and up to date details of all available services).

> "What patients and carers want to know about stroke is usually not the same as what health professionals think they should know." Stroke Association

Information about service users should accompany them through the system – designers of integration should seek to reduce the length and repetition of assessments, case history recording, etc. **Patient access to medical records**, control of who to share them with, and ability to correct them will help. These records need adapting to be fully capable of incorporating the recording of people's care plans – and their views, preferences and values – and the shared decisions they have already made.

Note – electronic records access is not the *only* answer. **Hand-held paper records** can be of more benefit to, for example, people with reduced capacity, children and young people, isolated frail elderly people, and chronically excluded groups (homeless, sex workers, travellers). Portability, not production format, is key.

Physical/mental health integration

Often left out of the discussion of integration is the joining up of physical and mental health services. People with long term conditions, especially those with more than one, often suffer from depression that goes untreated. Conversely, the physical health needs of people with enduring mental health conditions are rarely considered by mental health services, and there may be no assessment of the interaction between physical and mental conditions, nor the interaction of drugs for those different conditions[xix]. New investment in **GPs' education and awareness of mental health** and its links to physical health would be a major contribution.

Tariffs – mental health, end of life

Monitor and the NHS Commissioning Board must together decide the incentive system(s) for integrated care. Attention is focusing on the revising the main tariffs that reward hospitals for activity. However, there is equally urgent need to consider which groups of service users could benefit from having new tariffs for the first time. These arguments are strong for enduring mental health conditions and for end of life care[xx].

Social care withdrawal/uncertainty

Service users and carers whose needs span health and social care report increased uncertainty about their social care support; and that packages previously available to them are no longer so. Social care law and funding is to be dealt with in new legislation, but this will not help people through current and continuing crisis in social care. Integrated care must make **imaginative and innovative use of the 'whole budget'** available for health and social care. A review of continuing care entitlements leading to their extension to other groups and over time may be required[xxi].

Residential care

There is a danger of people 'disappearing' from integrated systems into residential care, of highly variable quality[xxii]. **Residential care provision should be integrated** with other services to ensure that frail elderly people's full needs are met[xxiii]. There is an urgent need for professionals to work together to **raise the quality of medicine prescription, use and management** in residential care.

Annex 1: implications for education and training

Top lines

Skill up doctors and nurses for: care co-ordination; care planning; working with other professionals across boundaries.

GPs need: expertise in working with 'population approach'; mental health awareness and education.

Expansion

People want care, and care co-ordination. This is relational. Integrated care must explicitly plan for who does the co-ordination, when, where and with whom.

Any professional being trained should be prepared for working in the context of the main demand for and use of health and care resources coming from people with complex, continuing conditions, using many services.

Care co-ordination cannot be assumed to be 'learned on the job' or the product of 'goodwill' between professionals. Professionals need training in the skills of working in multiprofessional teams across boundaries. Any professional groups that may take key responsibility for *being* the care co-ordinator should be skilled to do so.

Care planning is central in co-ordinated care. This requires a rounded set of skills, not just the 'communication skills' now included in medical education, and which are still oriented toward getting across what the doctor needs to say about clinical issues.

Skills for care planning are those needed for shared decisions. These include listening and 'eliciting' skills – to bring out and understand not just the clinical needs but other needs of the service user, their values and preferences, and their level of capability and willingness to take responsibility for their health and to share in decisions.

Care plans have been 'guaranteed' by successive governments and not materialised. Care planning will only become more common and widespread when the professionals working with service users understand its importance, its principles, and the techniques that can be used to involve people properly.

In particular, professionals need skills to work with people to help 'activate' them – that is, give them the information, knowledge and confidence to take on self management and self care at higher levels[xxiv]. Key techniques include 'health coaching' and 'motivational interviewing', which encourage people to take action while being non-directional[xxv].

Specifically for GPs: as a key liaison point (and potential co-ordinator/advocate) for people with long term conditions and adults with enduring mental health issues, GPs need greater education and training in mental health, and in the links between physical and mental health.

See the Annex B (public health) for text on why GPs need expertise in working with population approaches.

Annex 2: Implications for Public Health

<u>**Top Lines**</u>

Public health gains happen through good care planning.

GPs need to use population approaches in general practice (not just commissioning).

<u>**Expansion**</u>

There are many aspects to public health**,** including planning healthy environments and creating mass health awareness. But behaviour change often happens as a result of direct face to face consultations between people and professionals. People's 'own' doctors, nurses and allied health professionals are normally the reference point. There is a danger of separating 'public health' interventions from people's most common health contacts.

Integrated care approaches need to identify not just the individual clinical and patient experience outcomes they are aiming for, but also the 'public health' outcomes that can flow from better engaging patients in their own care and treatment.

Commissioners of integrated care need to be clear about the places in routine care where general health can be affected – in particular by 'patient activation' approaches. They need to specify the interventions that can made, and who should implement them.

There is a substantial evidence base for the effectiveness of patient-focused interventions[xxvi], which was the initial basis for the government's adoption of the patient movement slogan, 'no decision about me, without me'[xxvii].

'Best buys' for commissioners include[xxviii]:
- <u>health literacy</u> – personalised information for patients; Telephone counselling and helplines, tele-care, tele-health, tele-monitoring
- <u>treatment decisions</u> -- question prompts and coaching for patients; patient decision aids; patient access to records
- <u>prevention</u> -- proactive telephone counselling using motivational techniques; self-help programmes and websites
- <u>self management</u> -- Self-management education and support for patients with specific conditions, integrated into routine healthcare with the active involvement of people's main health professionals; interactive web-based self-management programmes; support for home-based self-monitoring (e.g. anticoagulation, blood pressure)

Commissioners need to agree with the service providers which professionals will implement these interventions.

General practice has a potentially larger role to play, as the holder of registered lists. Instead of waiting to see 'who comes through the door', general practice could use population-based approaches to identify and prioritise individuals and groups who are most likely to need proactive support to raise their health literacy and manage their health – and who otherwise will present to and use expensive interventions when needs become acute or more complex.

Web of care for a breast cancer patient

This 'web of care' was created for National Voices by Breast Cancer care to show the complexity of services that a patient must navigate. More webs of care can be seen at http://www.nationalvoices.org.uk/webs-care .
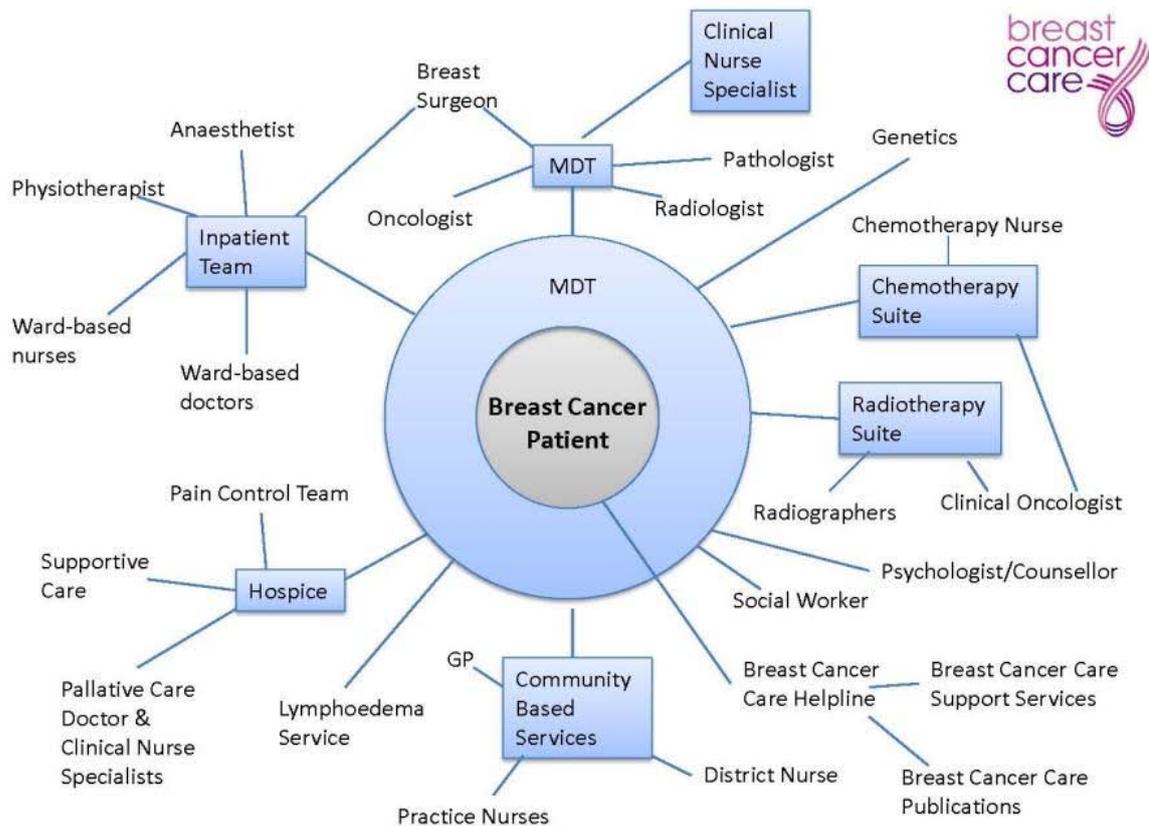
Process and acknowledgements

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Endnotes

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[ii] Picker Institute domains of patient-centred care reports, ibid

[iii] US Institute of Medicine, definition of patient-centred care, 2001

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[vii] These examples from the national survey of inpatients 2010, Care Quality Commission

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[ix] Survey of community mental health service users, CQC, 2011

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[xiii] Making care safer. Improving medication safety for people in care homes, Health Foundation, 2011

[xiv] Care home use of medicines study, DH, 2009

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[xvi] Time for change, Epilepsy Action, 2008

[xvii] On our own terms: the challenge of assessing dignity in care, Picker Institute Europe/Help the Aged, 2008

[xviii] Nuffield Trust, various papers on integrated care; DH chronic care model, 2006

[xix] Survey of community mental health service users, CQC, 2011

[xx] Final report of the palliative care funding review, 2011

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[xxii] 'On safety and suitability of premises, care homes had the lowest proportions of compliance, and also the highest proportions of major concerns', State of Care report 2010/11, CQC, 2011

[xxiii] Quest for quality, British Geriatrics Society, 2010, includes relevant recommendations

[xxiv] See the work of Professor Judith Hibbard, University of Oregon, on patient activation

[xxv] See for example, Ossman, S.S., (2004 May-June) Motivational Interviewing: A process to encourage behavioral change. Nephrology Nursing Journal. 31(3)

[xxvi] see www.investinengagement.info for analysis of 280 high level and systematic research reviews.

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