



Carers as Partners:

Improving Outcomes within Cancer Survivorship

May 2011

Definition of Carer

There is currently no single agreed definition of what is meant by the term “carer”. Within this paper we have used the definition contained within *Commissioning for Carers* [2009]ⁱ developed jointly by a number of carers and commissioners’ organisations including the Association of Directors of Adult Social Services [ADASS] and The Improvement and Development Agency [IDeA]:

A carer spends a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

Focus of this Paper

This paper considers the position of adult carers of adults with a diagnosis of cancer. It does not seek to consider the position of young carers of adults with cancers. Neither does the paper consider the position of parent and sibling carers of children with cancer. For some of the common cancers the majority of adult carers will be older people.

This paper does **not** consider clinical practice issues around cancer care, support and treatment. It does recognise, however, that clinical engagement with the issues covered is vital in improving overall patient and carer experiences and outcomes.

Audiences

The audiences for this paper are Directors of Adult Social Services and health and social care professionals and voluntary organisations working in the area of cancer survivorship.

Status

Professional practice, guidance, experience, skills and research are developing all the time. This paper has been produced in support of the improved outcomes set out in the national strategies for cancer¹ and the national priorities for carers². This paper seeks to complement existing guidance that may be in place and to promote discussion; evidence based practice and improved outcomes.

ⁱ **Fox, Alex**, *Commissioning for Carers and Commissioning for Carers: An Action Guide for Decision Makers*, 2009. The Association of Directors of Adult Social Services, The NHS Confederation, The Local Government Association, The Improvement and Development Agency, The Princess Royal Trust for Carers, Crossroads Care, Carers UK and the National Black Carers and Carers Workers Network, with Department of Health support.
www.idea.gov.uk/idk/core/page.do?pageId=6001526,

Carers as Partners in Cancer Survivorship

A PAPER FOR DISCUSSION

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1. THE CHALLENGE

This paper is aimed at two main audiences.

- Directors of Adult Social Services, carers' organisations and social care professionals working with people with long term conditions alongside cancer survivorship; and
- Clinicians, health and social care professionals and third sector organisations currently working with cancer survivors and carers.

The latter group is likely to be familiar with much of the supporting material in this paper. For them a key challenge will be around improving recognition, involvement and support of families and carers along the cancer survivorship pathway and afterwards. For the first group the challenge is to raise awareness of how the survivorship pathway is changing; the often critical role of carers within it and what this may mean for adult social care and universal services. Both groups face a further challenge. This is how to link greater awareness of the needs of cancer survivors, their families and carers to local approaches for personalised support of people with long term conditions within inclusive and supportive communities and tightened resource frameworks.

Few patients travel the cancer survivorship pathway alone. Carers often take on the care co-ordination role and the needs of patients with active or advanced disease can place significant demands on carers.³ The recent refresh of national policies suggests it is timely to think again about how involving carers as partners can help us achieve better care and support and improved outcomes within cancer survivorship. We also need to reflect on how we can assist carers to have a life of their own alongside their caring role. The policies are:

- *National Cancer Survivorship Vision*⁴ of January 2010
- *Improving Outcomes: A Strategy for Cancer*, January 2011 which replaces the 2007 Cancer Reform Strategy
- *Recognised Valued and Supported*⁵, published in November 2010 which sets out refreshed priorities for action whilst retaining the five strategic outcomes for carers from 2008⁶.

Of potential continuing relevance in this context are:

- the focus on supporting families, friends and carers within *The National Service Framework for Long Term Conditions* of 2005⁷;
- personalised care planning for people with long term conditions⁸ within the context of *Putting People First*⁹ and the recent sector wide concordat¹⁰; and,
- the *End of Life Care Strategy* of 2008 with special reference to *Chapter 5: Support for carers and families*¹¹

There has been a lot of excellent work on survivorship. The visibility of carers as partners in the care and support of patients with cancer, however, needs to be higher. We need to think again about how we can change what we do consistent with the three interdependent principles that now underpin plans for health and social care¹². They are at the heart of *Equity and Excellence*¹³ and the *Vision for Adult Social Care*¹⁴. We also appear to be at a point where we need to explore further how survivorship pathways can interface more closely in future with personalised support for people with long term conditions. As the *Cancer Survivorship Vision* states¹⁵:

"It is ... very important that the increasing numbers of people living with and beyond cancer, their carers and their families have the support and services they need to resume as normal a life as they can following cancer treatment."

The patient and carer experience of cancer care will be increasingly important as a measure of the quality and outcomes of survivorship services. If the quality of patient and carer experience is to improve, we must shift professional cultures around the role of families and carers as partners along the survivorship pathway. Family and carer issues need to become more visible if holistic and inclusive approaches to awareness, prevention, treatment and support for self managed cancer care within supportive communities are to develop.

More effective involvement of carers and families should make a real contribution to improving those aspects of survivorship care and support of most concern to patients and carers¹⁶. We need more evidence on what is working well locally. The guide produced by Macmillan Cancer Support in 2009¹⁷ offers a sound platform to better practice and improved outcomes. The 2008 Macmillan report¹⁸, however, showed how cancer survivorship also needs stronger links to adult social care. We need to reflect on this material and consider what might be done locally in the light of key facts¹⁹ about carers:

- *“38% of cancer carers spend more than 30 hours caring each week*
- *Nearly 3 in 10 cancer carers have been a carer for that person for more than 5 years*
- *A quarter of carers feel abandoned and a third experience anxiety*
- *Only one in five people with cancer felt their carers’ needs were met by health and social care.” [Macmillan Cancer Support, 2006-2009]*

These present health and social care with some real challenges. The initial cancer survivorship delivery programme provided for seven work-streamsⁱⁱ. The NCSI is co-ordinating a range of projects to provide evidence to support the principles of the Cancer Strategy and new care and support pathways following treatment. There are now project sponsors in the following areas: assessment and care planning, self management, consequences of treatment, work and finance and active and advanced disease.

In taking these projects forward we must think further about issues around partnership, involvement²⁰ roles for advocacy, individual emotional support, community enrichment and inclusion and reducing cancer inequality²¹. These issues are likely to be particularly important as we move towards more personalised assessment, information provision and care planning and supported self management that is envisaged.

Additionally, the refreshed cancer strategy encourages us to consider further how to strengthen links with local strategic partnership working as a mechanism for improving awareness, prevention and recognition of cancer. Local government has a potentially rich and key role to play within emerging local Health and Wellbeing Boards.

By working together to co-produce ways forward with patients, carers and communities there is an opportunity here to add value, give better value and secure the improved patient and carer experience and outcomes envisaged within national policy frameworks. It is about realising the linked visions for cancer care and for carers as part of an integrated approach.

**Dr. Graeme Betts,
Chair ADASS Carers Policy Network**

ⁱⁱ **Initial Cancer Survivorship Themes:** Assessment and Care Planning, Health and Wellbeing clinics; Managing Active and Advanced Disease, Consequences of Cancer and its Treatment, Survivors of Childhood and Young People’s Cancers; Work and Finance; Vocational Rehabilitation; Self Care and Self Management. Source: www.ncsi.org.uk

2. QUESTIONS FOR DISCUSSION

Equity and Excellence encourages us to think more about the evidence on what really matters to individual patients and carers in terms of experience and outcomes. Some questions we might explore in terms of improving experience and outcomes for patients with cancer and their families and carers are set out below. They are:

QUESTION ONE- Visibility of carers

How can we build on current work and promote better recognition of carers as partners in cancer survivorship, respond to their concerns and value their contribution?

QUESTION TWO – Information and advice

How might we, in partnership with the third sector, respond to needs for information for empowerment, exercise of rights, choice and control for patients and carers?

QUESTION THREE – Awareness and primary prevention

Early recognition and treatment are linked to survivorship. What areas might local government work on with others to raise awareness and empower people and communities to seize opportunities for promoting better health, early cancer risk recognition and reduction in avoidable, premature deaths?

QUESTION FOUR – Self-management of care

What examples from local practice might we draw upon to respond to patient and carer needs for consistent and accessible local support for self management of care?

QUESTION FIVE – Secondary prevention and recognition

How best can we promote secondary prevention and better recognition of signs and symptoms of further disease or late effects of treatment?

QUESTION SIX - Improving evidence and feedback

How can we improve knowledge and understanding about patient and carer experience within the cancer survivorship pathway and ensure this is used to inform what we do?

QUESTION SEVEN – Engaging adult social care

How can we raise awareness within adult social care of the interrelationships between universal services, more personalised approaches to long term conditions and cancer survivorship and joint health and social care pathways?

QUESTION EIGHT – Linking local action to Health and Wellbeing Boards

What are the potential synergies around survivorship within the NHS, social care and public health we would like to get on the agenda for proposed local Health and Wellbeing boards and for exploration with local people and communities?

QUESTION NINE – Engaging clinicians

How do we raise awareness of these issues with clinicians and integrate them with the commitments to ensure robust clinical standards and clinical outcomes as envisaged in the NHS Outcomes Framework?

Other areas will almost certainly emerge. A stronger focus on outcomes and what can make a difference locally for patients and carers and how we'll know whether we have can only be helpful. It may be, for example, that a specific section on carers on the NCSI Vision web page would both raise awareness of their needs and how they're being met.

BACKGROUND AND SUPPORTING MATERIALS

NOTE ON SUPPORTING MATERIALS

The sections that follow include material on policy context, carers' issues and the wider context within which the survivorship pathway is located. There are three main reasons for including this material within this short paper. They are:

- to provide an accessible summary of recent and current policy frameworks; and,
- to outline the evidence supporting the areas for discussion and others that might be explored; and,
- to contribute to awareness raising of carers and cancer survivorship within adult social care.

3. POLICY CONTEXT

3.1 Carers - Recognised Valued and Supported

Two of the key outcomes in the 2008 national strategy for carers were that:

“Carers will be able to have a life of their own alongside their caring role.”

“Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.”²²

In November 2010, the Coalition Government published a refreshed national strategy for carers: *Recognised, Valued and Supported*. This confirmed the 2008 Outcomes continued to be relevant but sharpened the focus on the following priorities:

- supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages;
- enabling those with caring responsibilities to fulfil their educational and employment potential;
- personalised support both for carers and those they support, enabling them to have a family and community life; and,
- supporting carers to remain mentally and physically well.

3.2 Improving Cancer Outcomes

The Coalition Government has agreed three interdependent principles to underpin its plans for health and social care. They are set out in the Foreword of *Improving Outcomes: A Strategy for Cancer* as follows:

- to put the patient or service user at the heart of the public services – transforming the relationships between citizen and service through the principle of *no decision about me without me*;
- to orientate the NHS, public health and social care services towards delivering the improvements in outcomes which matter – rather than measure processes which do not; and,
- to empower local organisations and professionals to deliver the freedoms to innovate and to drive improvements in service which deliver care of the highest quality for all patients and service users.

The outcomes strategy translates these underpinning principles into the 10 key steps needed to drive improvements in cancer outcomes. It sets out:

- ambitions for the quality of services to be made available to patients and service users, and to their carers and families, without exception;
- the support, information and choices which patients, and service users, and their carers and families, will receive to make best use of these high-quality services;
- the ways in which these services will be held to account for the outcomes they deliver through the NHS, social care and public health outcomes frameworks;
- the support which the Government will provide to assist these services to meet the outcomes for which they are accountable; and,
- the work which the Government will lead with non-state sectors to help shape services that meet the needs of patients and service users.

The focus is on how patients and service users can best be empowered to make the right care decisions themselves and how clinicians on the front line can be supported to deliver what matters to patients, users and carers: informed choices and high quality and improved outcomes

3.3 Cancer Survivorship Vision

The National Cancer Survivorship [NCSI] Vision, published in January 2010, sought to respond to improved cancer survival rates and what they mean for people living “*beyond and with cancer*”, their carers and their families. The aim was to ensure all cancer survivors get the care and support they need to lead as healthy and active a life as possible for as long as possible [See: **Appendix A** for Diagram of the pathway].

The NCSI vision is that people living with and beyond cancer, of whom there are an estimated 1.6 million in Englandⁱⁱⁱ, living in their local community, to secure five shifts:

- a cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and well being after cancer treatment;
- a shift towards assessment, information provision and personalised care planning;
- a shift towards self management, based on individual needs with the appropriate clinical assessment, support and treatment;
- a shift from a single model of clinical follow up to tailored support that enables early recognition of and preparation for the consequences of treatment as well as early recognition of signs and symptoms of further disease; and,
- a shift from an emphasis on measuring activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome Measures [PROMs] in after care services.

The NCSI has developed a series of principles, based on the model of care for people with long term conditions, that should underpin support. They include:

- A personalised, risk stratified pathway of care, following assessment and care planning.
- Support to self-manage, where appropriate, after appropriate assessment, support and treatment.
- Access to appropriate information and support including lifestyle advice, activity programmes and vocational rehabilitation.
- Access to case management support where appropriate for those with co-morbidities.
- Planned and informed transition from paediatric to other services.
- New pathways of care underpinned by care co-ordination, remote surveillance and rapid access to services if needed.

Action on the work-streams to deliver the five shifts²³ inherent in the NCSI Vision continues to progress forward. This is would appear to be a good point in time, therefore, to review potential issues for the carers and families of cancer survivors who will need support and services over longer periods from health and social care and wider local partnership arrangements tackling issues around health inequalities, community inclusion and economic regeneration and social disadvantage.

ⁱⁱⁱ Note: this paper does not consider issues relating to carers in Wales, Scotland or Northern Ireland

3.4 NHS Outcomes Framework – Domain 2 - Long Term Conditions

Improving cancer survivorship is part of Domain 1 of the NHS Outcomes Framework for 2011/12²⁴ published in December 2010. Enhancing quality of life for people with a range of long term conditions is part of Domain 2. Key improvement areas include:

- Feeling supported to manage their condition
- Time spent in hospital because of their condition
- Enhancing health related quality of life for carers

3.5 End of Life Care Strategy

The existing *End of Life Care Strategy [2008]*, to which the principles of the Survivorship Vision have been linked, identifies three key principles²⁵ as follows:

- carers are central to the team that cares for somebody at the end of life and they should be treated as 'co-workers' with the health and social care team;
- carers have their own needs. Those providing a substantial amount of care on a regular basis are entitled to a community care assessment by their local authority; and,
- the condition of the person who is cared for should not affect how the carer is treated, or the services the carer may be able to access.

The Cancer Outcomes Strategy confirms progress is being made with implementation. One of the issues is the inhibition on the part of the public and many professionals around conversations to permit care planning and understanding of patients' and carers' needs and wishes, which may not always be the same, around death and dying.

3.6 Healthy Lives, Healthy People

The 2011 public health white paper²⁶ outlines a new approach that aims to empower people to make healthy choices and give communities the means to address their own local needs. It recognises the responsibilities adults have around lifestyle but at the same time recognises that a range of factors constrain or influence what people do. Preventing poor health is a major theme along with the health inequality gap. There are new roles for local government. Jointly appointed Directors of Public health would be responsible for:

- promoting health and well being within local government
- providing and using evidence relating to health and well being
- advising and supporting GP consortia on the population aspects of NHS services
- developing an approach to improving health and wellbeing locally, including promoting equality and tackling health inequalities
- collaborating with local partners on improving health and well being, including GP consortia.

Local Health and Wellbeing boards would have a key role. A public health outcomes framework would sit alongside the NHS Outcomes framework described above. These domains link closely with the aims around awareness, recognition and preventable mortality within the Cancer Outcomes Strategy and for improving care for people with long-term care conditions.

4. CARERS AS PARTNERS IN CANCER SURVIVORSHIP

4.1 Introduction

Carers are people in their own right. As Gordon Conochie of the Princess Royal Trust for Carers said recently [Blog, 2011]:

"Carers are individuals with the same hopes and dreams that everybody has. We should not just be asking carers what can we do to support them as carers. Rather, we should be asking what we can do to support them as individuals whose choices may be limited by their caring role."

Macmillan Cancer Support has been supporting carers of people living with or beyond cancer for many years. They have made an enormous contribution to patient care and greater professional awareness of the needs of carers throughout the cancer survivorship care and support pathway. In an NCSI paper, Macmillan has stressed that:

"Supporting carers will enable them to have greater independence, choice and control and a better quality of life. As a consequence it may also enhance the quality or length of support that they offer the cancer survivor."²⁷

The Outcomes Strategy for Cancer [2011] included information on what the Coalition Government believed the public, patients, carers and clinicians are likely to want.²⁸ It is clear that systems need to join up in a more co-ordinated way around the needs of the carer and supported person to empower them both to live as full and active citizens. They include:

- good access to assessment and diagnostic services;
- access to comprehensive, reliable and balanced information for informed and appropriate choices about services, self care, and outcomes;
- empowerment to make choices and support in decision making that reflects clinical appropriateness and preferences for personalised care and treatment; and
- advice on how to minimise risk of cancer related problems, signs of recurrence and re-accessing services should this be needed.

Whilst not specific to the Survivorship Pathway, feedback from carers at the time of the preparation of the 2008 national carers' strategy generated three key messages:

- lack of co-ordination in the context of greater personalisation of services;
- carers working for systems that frustrate and annoy rather than having systems that support them; and,
- a need for improved professional understanding of the role of carers and the need to take carers' circumstances into account when arranging services and support.

The Survivorship Vision recognises that whilst no two people with cancer will have exactly the same priorities and needs, there are some common themes around needs. Many of these are equally relevant to carers such as:

- return to as normal life as possible or a new normal
- being cared for or treated as an individual
- treated as a partner in care
- having a sense of control over care and ability to make choices
- information to make informed decisions at each step on the care pathway

- what to expect and what to look out for
- side effects and available help
- reassurance about early detection of recurrence
- advice on benefits, work, education if needed
- knowing how to re-contact and access help
- knowing anxieties and fears will be taken seriously
- advice on how to stay well
- signposting to other services as needed
- health and social care working together – care is co-ordinated
- care close to home
- personalised care for as long as it is needed

The 2009 Picker Report²⁹ on the test community projects supports the identification of these as issues to be worked upon in taking forward the Survivorship vision. The overlap with similar issues for carers is outlined later in this paper [See: 4.4.].

4.2 Recognising Carers

Within adult social care, carers providing substantial and regular care have a right to assessment. Issues around work and education, for example, have to be taken into consideration alongside the sustainability of caring.³⁰ Whilst these rights do not extend to the NHS, there is a duty of co-operation. The NHS constitution³¹, however, makes two important provisions. The first is that:

“NHS Services must reflect the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate will be involved in and consulted on all decisions about their care and treatment.” Page 3

And later:

“The NHS commits ... to work in partnership with you, your family, carers and representatives” [page 7]

The cancer survivorship vision, however, simply states:

*“While this document refers to the needs of cancer survivors, this should be read as including the needs of their carers and families.”*³²

This is the only statement to this effect. In consequence, it is less easy to identify how the vision will recognise, value and support carers'. Just as the NCSI vision confirms that no two people with cancer will have exactly the same priorities and needs, the same is true of their carers. The needs identified following diagnosis³³, for example, have a strong resonance with identified needs of carers. Increased survivorship also has implications for employment, independence and roles within communities.

4.3 Supporting Families and Carers

The survivorship pathway for many patients will be a joint one, shared with their carers and families. Carers will also have needs falling for consideration by health and social care. The need to strengthen the carer and communities dimensions of the NCSI vision was acknowledged in the launch presentations and in a paper by Macmillan. It is given added emphasis by the publication of *Equity and Excellence* in July 2010. This states:

*“The system will focus on personalised care that reflects individuals’ health and carer needs, supports carers and encourages strong joint arrangements and local partnerships.”*³⁴

A key point to keep in mind throughout the survivorship pathway is that not all carers are family members and not all family members are carers. Recognition and support for the caring role is vital. Many carers will take on that role and they will also have their own needs, fears and may have their own pressures around health, employment or arising from tiredness and the pressures of caring. They will have varying levels of need and support depending on their circumstances and that of the cared for person.

Patient reported outcomes measures [PROMs] are seen as important alongside clinical indicators. As part of this, NCSI is developing a national survey of cancer survivors to be piloted in 2011. It is intended that this and wider routine use of PROMs will enable commissioners and providers to understand better the quality of life and outcomes issues to inform commissioning and provision.

The risk of deterioration in carers' health and well being as a consequence of their caring responsibilities is well documented³⁵. The NHS outcomes framework states:

“Carers: to recognise the vital role they play in supporting people who are ill. The role of the NHS is relation to carers centres on making sure they remain in good health, or that their health-related quality of life does not deteriorate due to their caring responsibilities.”

Cancer survivorship, however, involves the whole family. Scope for “*whole family approaches*” can be particularly relevant to joint pathways involving NHS and social care. Family relationships may change. Carers and patients may suffer financial and emotional pressures that impact on ability to sustain their health and independence. There may be issues around continuing or remaining in work or for roles within the community.

4.4 Carers and Follow-Up Care

The Picker Institute was commissioned to examine patient and carer views of health and social care services following treatment for cancer. The resulting report³⁶ confirmed a need for support for their partners, carers, family and friends. This was predominantly about emotional support but practical aspects of providing care and support to the patient also arose. Whilst a small group, the messages from carers were around:

- Importance of rapid access to specialist care
- Value of single points of contact and continuity
- Problems with contact points and lack of knowledge about others
- Feelings that GP as a point of contact for concerns cannot replace specialist follow up care
- Information on treatment and what to expect afterwards had improved
- Unmet information needs around follow up appointments, side effects, check ups, general health and well being, work and benefits
- Limited availability of psychological support and help with more practical aspects of providing care
- Concerns about patient managed follow up and the fear that not all patients would get or seek help when they needed it
- Negative perceptions of group follow-up

4.5 Embedding in Personalised Care Planning

The evidence used in developing the NCSI Vision suggests a stronger focus on professionals working together with patients and their carers to achieve the outcomes they want for themselves.

In promoting “*nothing about me without me*”, *Equity and Excellence* reinforces earlier messages that health and social care professionals need to support people and their carers in having a real say and for them to be treated as equal partners in care planning discussion. Personalised care planning recognises that there are other issues in addition to medical needs that can impact on health and well being of the patient, their family or carer. In moving forward we need to encourage holistic processes that see the cancer survivor “in the round”.

The *National Service Framework for Long-term Conditions [2005]* had some messages that appear relevant to improving care experiences and outcomes within survivorship. It suggested:³⁷

- all carers are partners in care and be treated as such; including training and support to learn new skills;
- all carers should have a choice about their care and support role; its commencement, changing nature and its sustainability;
- flexible, culturally appropriate and responsive services should be available for all carers; including emergency situations and breaks from caring;
- all carers have a written plan agreed with them and reviewed regularly and an allocated contact person to talk to.

The key elements and benefits of the care planning process for long term care³⁸ as envisaged in 2005 are set out in **Appendix B**. As cancer survivorship is seen more in the context of long term conditions we can use these insights. One such was that staff working with people with long term conditions would receive carer awareness education and learning to facilitate carer involvement in planning and delivery.

Empowerment of cancer patients, families and carers, however, is about both attitude and approach within care pathways. It needs to involve everyone and an understanding that, as has been stated by Harry Cayton, for long term conditions³⁹:

“When you leave the clinic, you still have a long term condition. When the visiting nurse leaves your home, you still have a long term condition. In the middle of the night, you fight the pain alone. At the weekend, you manage without your home help. Living with a long term condition is a great deal more than medical or professional assistance.”

Access to and availability of emotional as well as clinical and practical support is important to families and carers. Few, however, appear to receive such support and the evidence from pilots is generally positive. Its potential in helping to sustain self-management of care and timely follow-up care should be explored further.

4.6 Valuing Carers - Involvement

A recent paper on user involvement in cancer care reviewed policy and principles surrounding involvement. It identified six principles⁴⁰ to underpin effective user involvement. They can be summarized as follows;

- Systematically collected information to inform change
- Valuing diversity; involving all
- Involvement embraces operational level interventions
- Partnership working and other methods used to promote change
- Involvement is used to empower and to exercise influence
- Involvement has professional support and has stable resource base
- Quality is pursued from a “patient centred care” perspective

Effective involvement, therefore, is about patients, carers and families:

- Having their voice heard
- Being valued for their knowledge and skills
- Having involvement in service evaluation and feedback
- Participation in service planning

Involvement and shared decision making with patients and carers means these are critical elements to achieving the aims of *“Equity and Excellence”*. The key message of *“Nothing about me without me”* means we need to be sure we are doing these things. The proposed NHS Commissioning Board will champion patient and carer involvement but we need to think local and personal as well. The White Paper also states:

“[we] have barely started to realise the potential of patients as joint providers of their own care and recovery” [p.13]

The survivorship vision offers real opportunities for us to test and take forward this concept of co-producing outcomes within and across care pathways and for the inclusion of family carers. Health and social care scrutiny can be used to clarify local issues and identify emerging practice that leads or could lead to better outcomes.

Communities and professionals within them also have a role. In some areas cancer patient and carer forums have developed with support from the NHS and adult social care. The aims of the Lincolnshire forum, for example, are:

- To influence cancer services and improve care at all levels.
- To enable patients and carers to feel valued in the contributions they can offer us.
- For professionals to have a "reality check" and keep what matters to patients and carers at the centre of our care and work.

Appendix C contains a model of patient centred and supportive care that includes carers. It helps to focus on how care and support should recognise people as individuals and the value of holistic and inclusive arrangements that are reflected in *Equity and Excellence*. This approach is relevant along the whole survivorship pathway. **Appendix D** outlines a model for patient and carer involvement which can be used to inform local discussions and practical experience.

4.7 Empowering Carers - Information

Information, as *Equity and Excellence* recognises, improves accountability, and combined with the right support *“...is a key to better care, better outcomes and reduced costs”* [p13] The National Institute for Clinical Excellence [NICE] recognises that most patients and carers want and need information about cancer and its treatment throughout the patient pathway⁴¹. The point is made that patients and carers cannot express preferences about care and make choices about involvement unless they have timely and appropriate information. Patients and carers⁴² need to be:

- treated as individuals
- have their culture, lifestyles and beliefs respects
- have their voice heard and be valued for their knowledge and skills
- receive high quality information
- know what options are open to them
- be involved in information development.

It is probably no accident that the first page of the Macmillan Cancer Support guide for carers covers information and support.⁴³ The main messages are that:

- getting reliable information in a suitable format helps people to feel more in control the situation;
- having information can help reduce feelings of isolation and offer reassurance that help is available if it is needed;
- information can make it easier to anticipate some of the difficulties that may arise and to be prepared for them: not just at diagnosis but along the whole of the survivorship pathway;
- information can help get the right support at the right time;
- speaking to people who are going through similar situations can be supportive and involvement can lead to better care and a better understanding of the particular cancer;
- knowing more about what to ask, who to ask and where to go can help reduce stress and worry.

Timely and relevant information is essential. There may be issues around staying in or returning to employment; rights around flexible working and about benefits and financial support. There is some evidence that these aspects may not be picked up. Macmillan Cancer Support has shown how individual outreach support can have positive impacts⁴⁴.

4.8 Carers - Information for Self Care & Management

Providing people with quality, timely and relevant information is a critical success factor for sustainable self care and self management. Clear arrangements that involve both patients and carers for symptom recognition, risk management, crisis and contingency situations can do much to sustain self-care and management.

Rightly, information provision is a one of the key shifts in the Survivorship Vision. Oral information sharing will remain important but this will need to be reinforced by more personalised and tailored written information. Information and involvement will be critical at key stages of the care pathway: referral, diagnosis, end of first treatment, remission, reoccurrence and end of life. Families and carers should also be involved in development of information materials. Feedback on accessibility, timeliness and utility should be sought. Critically, information needs to be kept up to date; be in a range of formats; meet cultural and language needs and be clear about follow up and discussion.

Health and social care professionals have an important role in growing an understanding of carers' needs and what can improve their experience within the duration of survivorship pathway. The BMA has identified⁴⁵, in more general terms, a number of areas where support and learning could be helpful in supporting self care:

- moving and handling
- relevant nursing skills
- use of equipment
- continence care
- stress management
- helping carers to look after themselves.

All these areas are relevant to the survivorship pathway; especially consequences of cancer care and treatment, managing self care and overall health and well being. Involvement of carers and information can be helpful in sustaining self care and management. Knowing where to turn to for advice can assist in managing concerns and sustain care at home.

Families and carers of people approaching the end of life often have a vital role in the provision of care and support. They need to be involved and informed as well as receiving recognition that they have their own needs. Information has a critical role in this context and a carer's right to an assessment should be recognised and needs reviewed. As the *End of Life Strategy* states:

*"Carers need information about the illness itself and what to watch out for, if they are to carry the ongoing responsibility for care. They need factual information to plan their own lives and in order to be prepared for different eventualities. This may include information on the likely course of the illness, benefits, work issues and what to do when someone dies and other practical matters."*⁴⁶

Macmillan Cancer Support has also shown how practical and emotional support for end of life carers can facilitate patient wishes around their remaining days at home and improved team working.⁴⁷

4.9 Engaging with Adult Social Care

In the past, the social care needs of people with cancer and their carers have had a low profile. This applies within both health and social care and embraces wider issues around universal services inherent in the thinking that underpins *"Putting People First"*⁴⁸ and the more recently published *"Think Local, Act Personal"*⁴⁹.

A conference^{iv} held in December 2009 highlighted these wider issues. Cancer patients and their carers are often not referred to adult social care services. There were continuing concerns that even when they were that specific needs were not met because of high care thresholds. Yet, people have emotional and practical support needs beyond the treatment of their cancer. In 2009 Macmillan Cancer Support published a report on cancer and social care: *"Social Care for Cancer"*⁵⁰. Some of the findings posed a number of challenges for adult social care. They were that:

- People with cancer and their carers have social care needs and these vary considerably along the cancer journey and between individuals.
- People with cancer and carers do have access to social care services but the degree of use varies considerably.
- Many people with low or moderate needs fall outside of the social care thresholds for support and rely on family and friends for the emotional and practical support they need.
- A number of barriers remain which impact adversely on the commissioning of services for people with cancer and include:
 - individual awareness of available care and support; lack of understanding around eligibility; and, lack of willingness to ask for help;
 - signposting to available support and resources for commissioning and integration of personalised care and support between health and social care;
 - existing local frameworks for care services and extent of discussion around change and evidence to support this.

At the same time, the report was able to identify the potential for innovative practice. An example was a social care co-ordinator based in cancer services able to spot purchase short term care for people affected by cancer with low or moderate needs.

^{iv} Meeting the Social Care Needs of People with Cancer and their Carers, Portland Place, London, 7 December 2009 [Institute of Healthcare Management and endorsed by ADASS]

Another, *Macmillan Solutions*⁵¹ is an umbrella of available support and consists being piloted and has four main elements [although not all need be taken up]:

- Narrative assessment
- Buddying
- Information
- Individual Budgets
- Skill swaps

Key responsibilities for adult social care centre on:

- Assessment
- Provision of Breaks [also available from Health]
- Care and Support Services
- Joint Development of care pathways with health

Much of the information available on the internet, however, tends to focus on the more traditional forms of help from social care: sitting services, meals, adaptations. Assessment is not always an easy area for some carers. There is rather less information on cancer sites around direct payments and personalised care options that are increasingly available. If, as indicated by the limited evidence available, awareness and take up are low then health and social care may need to do more to inform individual:

- awareness of what is available
- perceptions of unmet needs
- understandings of eligibility for support
- perceptions around likely usefulness
- beliefs about what seeking help means for them
- views about the likelihood of their situation continuing unchanged

This needs to be a joint task requiring something of a cultural shift for both health and social care professionals. It requires an ability to work across sectors to achieve it. There is also a role for greater community awareness of messages concerned with prevention, treatment, self directed support and survivorship

When it comes to treatment, most people if they have to go into hospital want to be there for as short a period as possible. There will be pressure to go home and increasingly we will be seeing cancer services delivered closer to home or at home. In terms of hospital discharge processes recent work by ADASS and the Princess Royal Trust for Carers points to the value of holistic approaches that can lead to more sustainable outcome for patients and carers.

As the population continues to age it is likely the incidence of cancer may continue to grow. Adult social care and support for older people aged 75 and over is considerable. Greater awareness of issues around cancer survivorship issues along the pathway could be greater than it has been in the past. This is not only a workforce development issue for us but also one for local strategic community needs assessments.

4.10 Equalities

Carers are as diverse a group of people as cancer survivors. Caring will find expression in many different ways at different times along the Survivorship Pathway. The impact of caring will differ according to the circumstances of the cared for person, cultural expectations, changing family structures and within different communities.

There can be particular difficulties for patients and carers in communities affected by economic and social disadvantage and in families on benefits. In addition, some groups, such as lesbian, gay, bisexual and transgender [LGBT] may have particular concerns around recognition of their role and involvement along care pathways.

The Picker Report also looked at equalities issues. It noted that there were “*statistically significant differences between ethnic groups across a number of areas of care*”. They added the caution, however, that small numbers may affect this finding⁵².

Carers from black and minority ethnic groups [BME], therefore, may experience a double disadvantage. The issues appear to be around access, information and contact. A review by ADASS published in 2010⁵³ identified a need for more evidence around the experience of BME carers in the context of hospital discharge. This and other aspects of that paper contain similar messages to the Picker Reports. A report by the National Cancer Equality Initiative published in March 2010 indicated that:

“...although cancer services have improved for everyone the progress in achieving better cancer outcomes has been uneven”⁵⁴

The work of NCIS has been positive.⁵⁵ It is clear that there are a range of inequalities and that disadvantaged communities may have less awareness of cancer signs and symptoms, lower take up of screening and later presentation. Poorer experience of care was reported by BME groups and men with prostate cancer. Improvements in mortality were slower in older people than younger people.

Overall, the message is that there needs to be improved information capture on equalities within the NHS. This includes issues such as staff awareness and the need to champion good practice if the risk of double disadvantage for carers from disadvantaged communities, marginalised groups or from BME groups is to be reduced. It is also one that finds expression in *Equity and Excellence*. This states:

“We will seek to ensure that everyone, whatever their need or background benefits...”
[p.3]

This work on equalities is part of a wider approach to tackle health inequalities of which reducing cancer inequalities is a part. There is a role for local government here. Some progress has been made. We need to bear in mind that, just as assumptions are sometimes made about carers generally, there may be assumptions about caring capacity by particular black or minority ethnic groups and communities. We need to ask, learn from people and to get regular and systematic local feedback to inform awareness raising and assurance mechanisms around patient and carer experience and outcomes.

5.4 Local Government and Local Partnerships

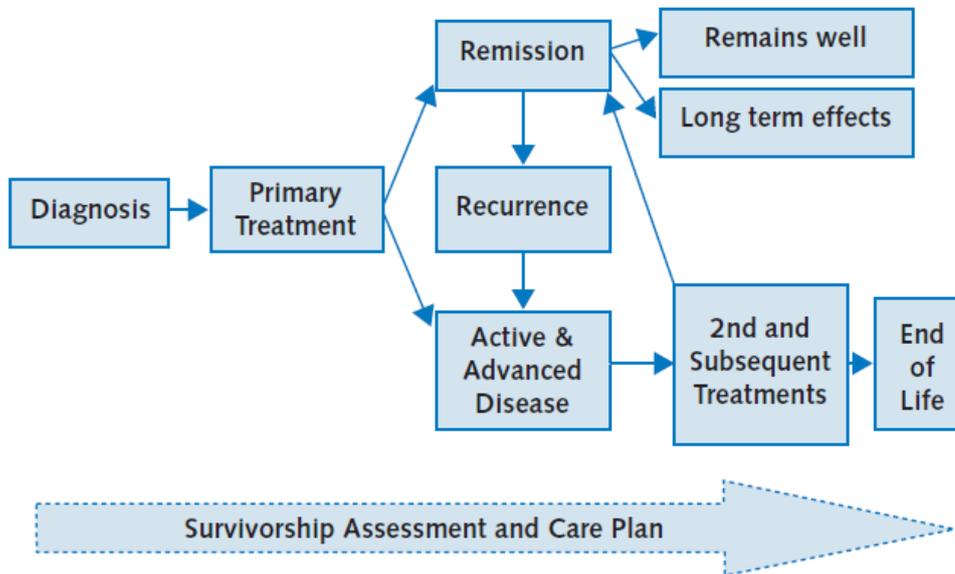
*Equity and Excellence*⁵⁶ proposed the transfer of PCT responsibilities for local health improvement to local authorities. Local Directors of public health, jointly appointed with the public health service, would be encouraged to break down barriers between health and council funding to encourage preventative action.

The proposed establishment of Local Health and Wellbeing Boards confirmed in the White Paper on Public health⁵⁷ offers real opportunities for councils and health to work together and to build upon existing local partnership working and capacity for co-production with local people. There is a real partnership role for local government in terms of incidence, prevention, treatment and survivorship. Local government can help support messages around prevention concerned, for example, with smoking, diet, sun protection and awareness.

APPENDIX A

National Cancer Survivorship Vision

The Survivorship Pathway:



Source: NCSI Vision, p 23

The Five shifts in care and support for people living with and beyond cancer

Five shifts in care and support for people living with and beyond cancer:

1. a cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and well-being after cancer treatment.
2. a shift towards holistic assessment, information provision and personalised care planning. This is a shift from a one-size fits all approach to follow up to personalised care planning based on assessment of individual risks, needs and preferences.
3. a shift towards support for self-management. This is a shift from a clinically led approach to follow up care to supported self-management, based on individual needs and preferences. This approach empowers individuals to take on responsibility for their condition supported by the appropriate clinical assessment, support and treatment.
4. a shift from a single model of clinical follow up to tailored support that enables early recognition of the consequences of treatment and the signs and symptoms of further disease as well as tailored support for those with advanced disease.
5. a shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome Measures in aftercare services.

Source NCSI Vision, p 26

APPENDIX B

Long Term Care: Care Planning Process – Key Elements

Box 1: Key elements of the care planning process

The care planning process:

- puts the individual, their needs and choices that will support them to achieve optimal health and well-being at the centre of the process;
- focuses on goal setting and outcomes that people want to achieve, including carers;
- is planned, anticipatory and proactive with contingency (or emergency) planning to manage crisis episodes better (for those with complex needs);
- promotes choice and control by putting the person at the centre of the process and facilitating better management of risk;
- ensures that people, especially those with more complex needs or those approaching the end of life, receive co-ordinated care packages, reducing fragmentation between services;
- provides information that is relevant, timely and accredited to support people with decision making and choices (eg supported by an **Information Prescription**);
- provides support for self care so that people can self care/self manage their condition(s) and prevent deterioration (eg supported by **Your Health, Your Way**);
- facilitates joined-up working between different professions and agencies, especially between health and social care; and
- results in an overarching, single care plan that is owned by the person but can be accessed by those providing direct care/services or other relevant people as agreed by the individual, eg their carer(s). This may be a written or electronic document or may be something that is recorded in the person's notes. The important aspect of this is that the care planning discussion has taken place with an emphasis on goal setting, equal partnership, negotiation and shared decision making.

Personalised Care Planning – the benefits

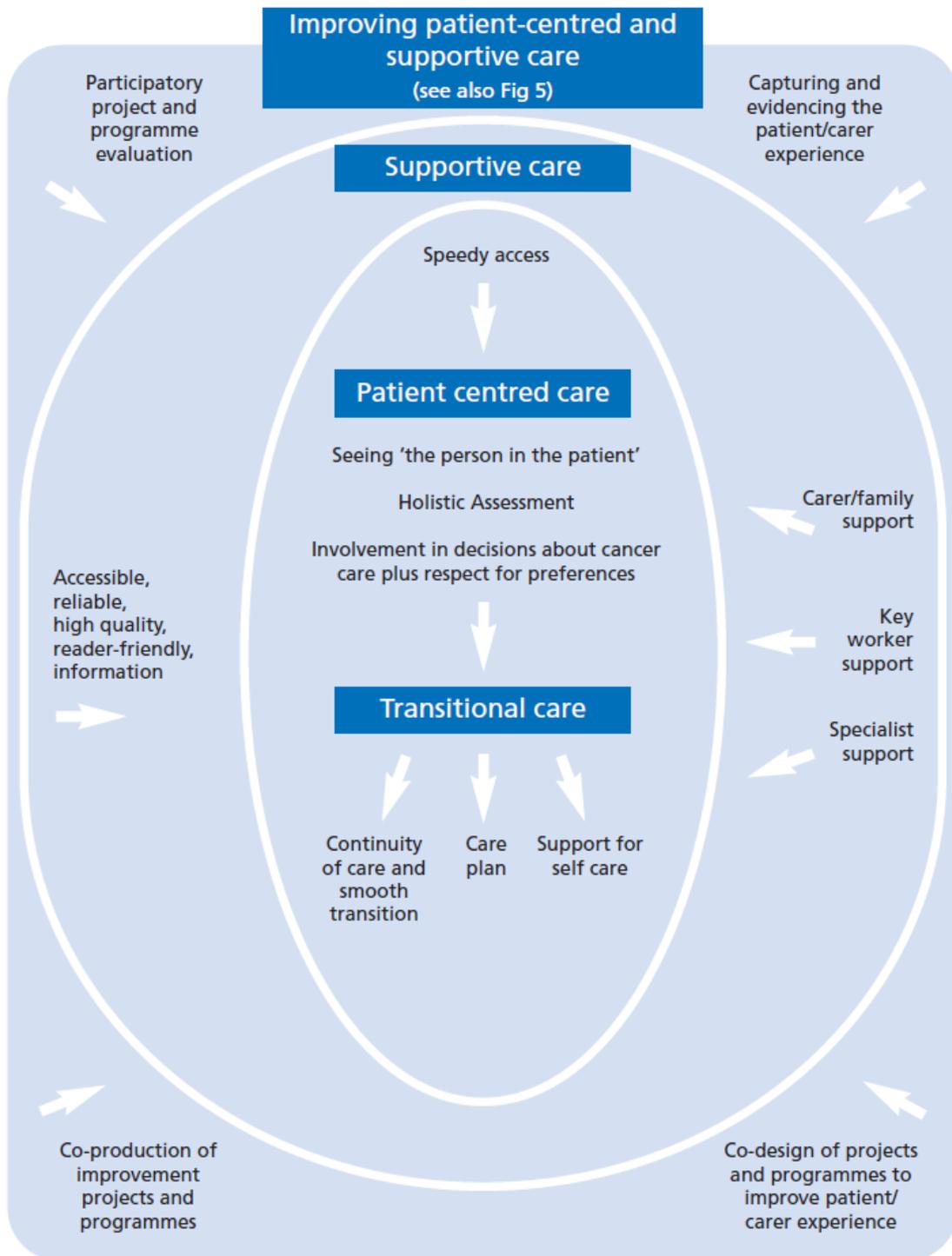
- embedding the personalisation of care and services 'adding life to years';
- promoting health through information and self care, people staying healthier for longer and therefore 'adding years to life';
- promoting independence and achievement of other goals such as returning to work or living independently;
- reducing health inequalities by standardising care across the country;
- promoting integration and partnership working;
- stimulating genuine choices, and those choices feeding into commissioning decisions;
- promoting a more planned, proactive approach to health and social care services;
- efficiency savings, eg reductions in hospital admissions, outpatient appointments and GP consultations; and
- improved user and staff satisfaction, including fewer complaints.

Source: Supporting People with Long Term Conditions, 2009, pages 5 & 11.

APPENDIX C

Service User Involvement in Cancer Care

Fig 4. Promoting patient centred and supportive care

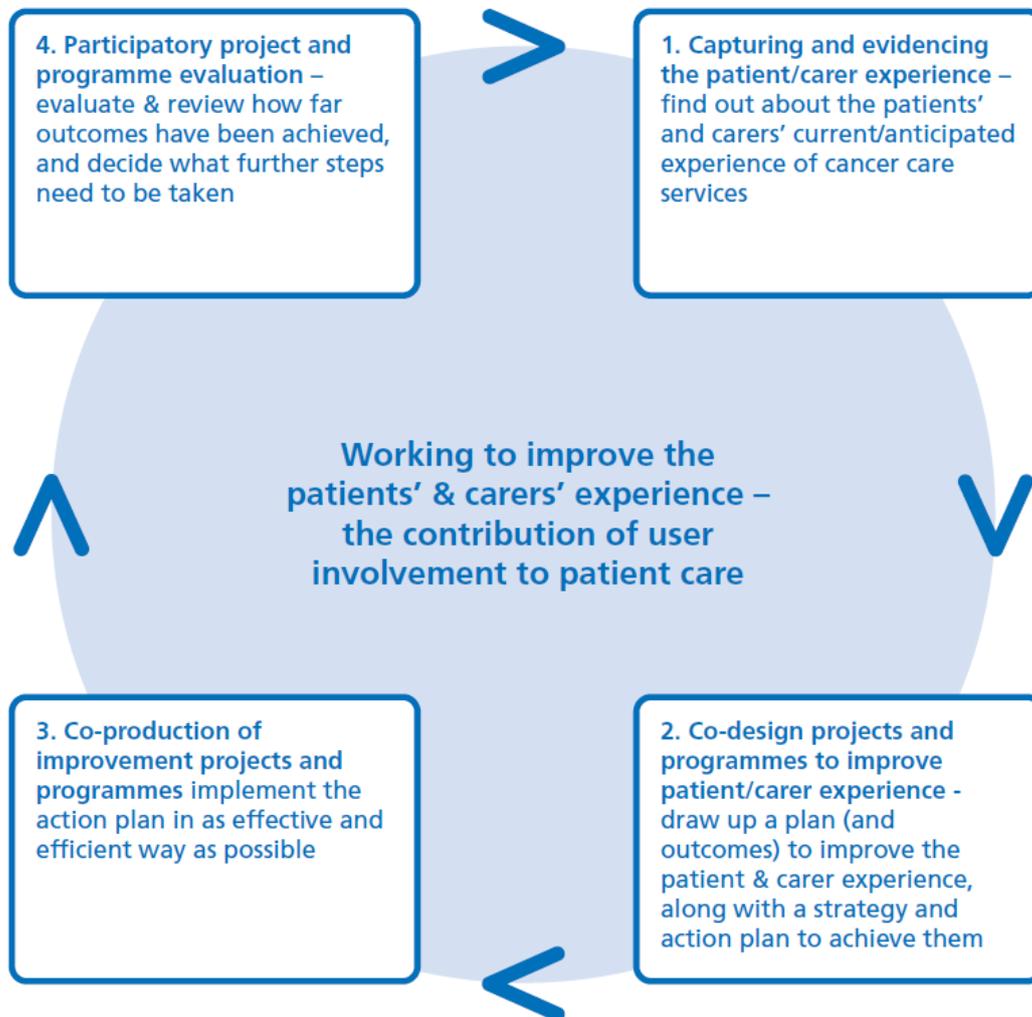


Source: Butcher, Hugh, Chapter 4 p. 27

APPENDIX D

User Involvement Cycle

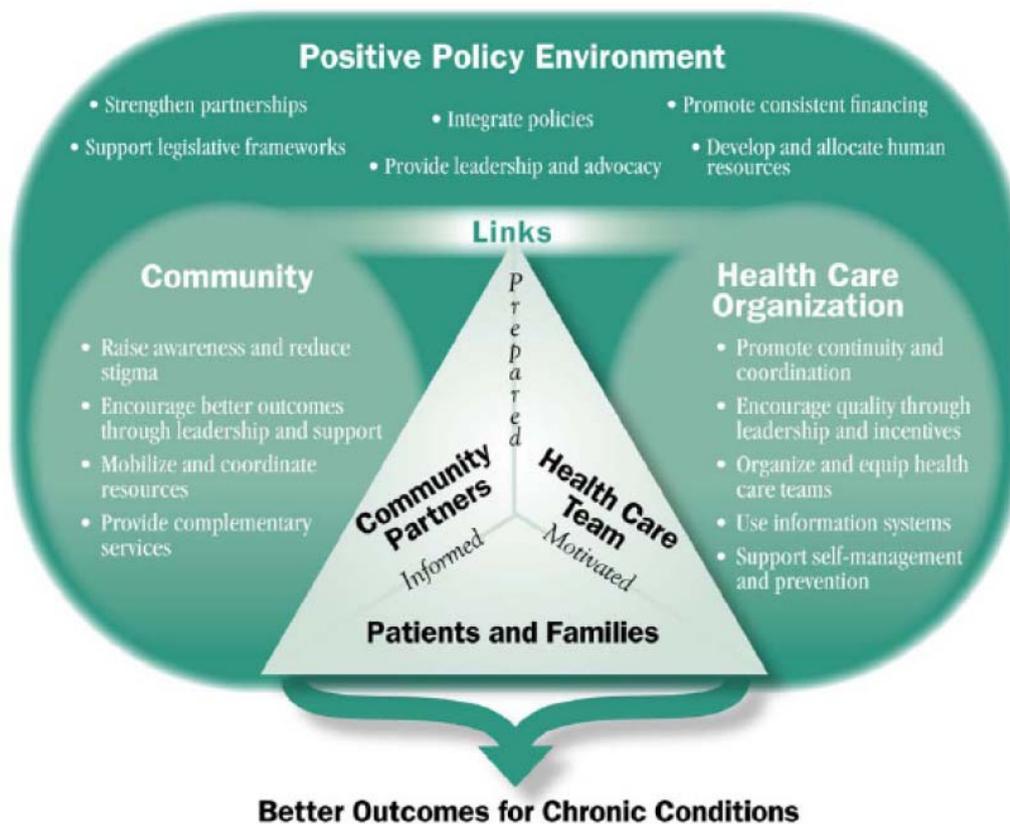
Fig 5. The user involvement improvement cycle



Source: Butcher, Hugh, Ch. 4 p 30

APPENDIX E

Innovative Care for Chronic Conditions Framework [2002]



Source: WHO, 2002 reproduced in *Improving Care for People with Long Term Conditions, A review of UK and international frameworks*, University of Birmingham HSMC, NHS Institute for Innovation and Improvement 2006. p. 9

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Association of Directors of Adult Social Services

The Association of Directors of Adult Social Services (ADASS) represents directors of adult social services in local authorities in England. Directors of Adult Social Services have statutory responsibilities for the social care of older people and adults with disabilities, while over 50 per cent also run social housing departments. ADASS members might also share a number of responsibilities for the provision and/or commissioning of housing, leisure, library, culture and arts services within their councils.

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