

September 2009



Planning Care —the Patients' Perspective

A national survey of health advocacy groups

A report prepared for the
Royal College of Nursing and National Voices
by PatientView

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Foreword

A key pledge in Lord Darzi's June 2008 Review of the NHS is that every patient with a long-term condition will be provided with a care plan by June 2010.

Why this survey?

This nationwide survey was jointly commissioned by National Voices (an umbrella organisation established in September 2008 by and for the voluntary sector) and the Royal College of Nursing as one of the first moves to discover what patients and their representative organisations understand and think about the government care-plan initiative. Care plans are a form of patient-friendly 'roadmap' that records the treatment and social support that a person with a long-term illness needs. They are meant to be drafted in consultation with the patient, and are also intended to be flexible, adapting to any changes in the patient's personal circumstances. Care plans have three main aims: to improve efficiency and coordination among health and social services; to improve the patient experience of these services; and (hopefully) to improve patients' health outcomes.

About the methodology

This online survey was undertaken between June and July 2009, and primarily approached local groups that represent carers, people with a disability, and patients (all were listed within PatientView's database of such groups). Many of the respondents are branches of national umbrella groups that are member organisations of National Voices.

The survey examined respondents' awareness of care planning/care plans (in reference to the government commitment). Some 430 groups responded (321 of which completed the questionnaire in full). The respondent groups seek to represent the views of well over one million patients with long-term conditions. The survey made every effort to include the views of groups that represent the interests of minorities, including people with a disability, with a rare disease, from different ethnic backgrounds, or those caught in a poverty trap. The main geographic focus of the survey was England (the regional remit of National Voices).

The survey results should not be regarded as an exhaustive examination of public attitudes to care planning—rather, a local-level snapshot of how well the NHS is progressing toward the government target of care plans for everyone with a long-term condition by mid-2010.

National Voices and the Royal College of Nursing would like to extend their thanks to everyone who volunteered their valuable opinions to this study, and to PatientView, the research and publishing organisation that designed and administered the study, and which drafted the findings.

Yours faithfully,

Howard Catton, Head of Policy Development and Implementation, Royal College of Nursing
and

Mark Platt, Director of Policy and Public Affairs, National Voices.

Key recommendations

as a result of survey findings

- Numerous diverse patient (and other health-related) groups that represent the interests of people with long-term conditions up and down the country believe that care plans have many positive contributions to make to the quality of life of patients, and to the clinical outcomes of their treatment. Many of the survey's respondent groups welcome the effects of care plans (from personalisation to dignity) that are entirely in tune with government objectives.
- Care plans clearly have widespread appeal among patients and their representatives—one reason why the government ought to honour its commitment to supply care plans to all individuals with a long-term condition.
- Current levels of consultation with patients in the design and implementation of individual care plans is shockingly low. Further efforts must be made to engage with patients during the entire care-planning process.
- Health professionals require more resources and training if they are to implement and manage care plans. Respondent patient groups insist that dedicated staff are needed for the job.
- Specialist and community nurses have an important role to play in supporting the care-plan process, and could be embraced in policymaking in this area.
- If the Government is truly to deliver the commitments that it has made, including those contained in the NHS Constitution, more must be done across all patient pathways to ensure staff are resourced to deliver, and patients are informed to be engaged, so that care-planning is embedded in the culture and practice of the health service.

"This survey shows how important care plans are to people living with long-term conditions and why greater awareness of care plans and support is needed. Even where care plans are being delivered many patients report they have little involvement. It's time that the government realised that a major commitment for people with long-term conditions is in danger of becoming a meaningless policy statement."

"In a time of economic downturn, care plans are fundamental to delivering services that match need and therefore ensuring that health services are delivered cost-effectively. Ultimately they will help the government meet its ambition for quality, innovation, productivity and prevention."

Mark Platt, Director of Policy and Public Affairs, National Voices

Introduction

According to NHS Choices (the online information service provided to the public by the Department of Health), everyone who has a long-term condition can take part in the making of their own care plan. The NHS Choices website states:

“The care plan is to help assess what care is needed, and how it will be provided. By talking about your care plan with the GP, nurse, or social worker who will write it, you can say how you want your health to be looked after and choose what’s best for you. The care plan will be based on what you want to do, so that you’re in control. The care plan is to help you, rather than the GP and other healthcare workers that look after you. It will state your health, social and personal needs, and how those needs will be met.”

Dr Peter Carter, Chief Executive and General Secretary of the Royal College of Nursing, notes two important benefits of care plans:

“When a patient is diagnosed or living with a long-term condition, they need to have a clear understanding of what support they can expect, as well as having the opportunity to make informed choices about their own care. This includes all of the care on offer from hospital, community and social care services.”

About the survey respondents

Appendix (pages 17-18) contains a list of some of the organisations that took part in the survey and which asked to named as respondents

- 430 patient and health-focused groups drawn from across England responded to the survey.
- 321 groups completed the entire questionnaire.
- The majority (61%) of respondent groups work at a local level.
- Taken together, the respondent groups represent over 1 million patients with a diversity of long-term conditions (from mental health and cancer, to heart disease or HIV/AIDS).

Care plans—their value

This survey finds that most patients and their representatives believe that care plans can offer a wide range of advantages—if the plans are properly designed and implemented. In some circumstances (such as end-of-life care), and with some conditions (such as cancer, diabetes and mental health problems), the respondents believe that care plans are “highly beneficial”.

My personal experience of treatment and care plan has to be excellent. I fully believe that it is my care plan, and that I have most of the say in how it progresses. It has helped me take ownership of my treatment and care plan. In mental and substance abuse, care planning has been used for a number of years.

Almost three quarters of the groups taking part in the survey maintain that care plans, if properly designed and implemented, could increase patients' satisfaction with their treatment and care, as well improve quality of life (taking in elements such as dignity and privacy for patients). Some 73% of the respondent groups believe that patients would receive useful information with care plans. Over two thirds see care plans as important for providing patients with choices in treatment and care. More than half are certain that care plans will also help patients comply with treatment, and will improve clinical outcomes.

Several care plans for different long-term conditions have been formulated by the Department of Health. In four of the 15 subject areas that the survey provided as examples—cancer, diabetes, end-of-life care, and mental health [see table on next page]—the majority of the respondents who claim to be familiar with the government-formulated care plans think that these are either “beneficial” or “highly beneficial” from a patient perspective. A significant number of respondents state that it is still too early to make a judgement on how valuable government-designed care plans might be in the remaining 11 specialties.

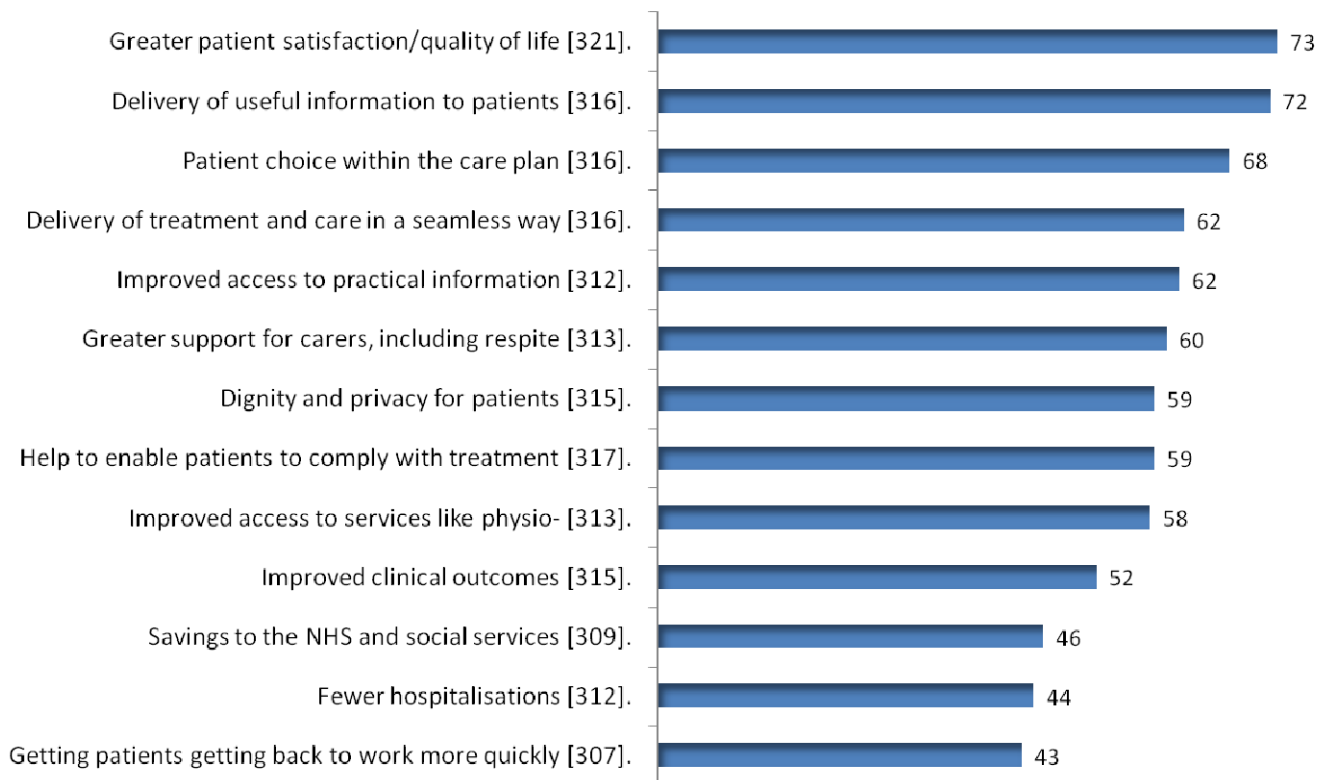
Several care plans have been proposed by the Department of Health, following a period of consultation. If you are familiar with any of the plans listed below, could you indicate how beneficial they have been from the patient perspective?

| Medical condition <i>[Number of groups providing an opinion in this category]</i> | % of respondents who say that the care plan is “beneficial” or “highly beneficial” |
|--|--|
| End-of-life care [66]. | 67 |
| Cancer [77]. | 60 |
| Diabetes [58]. | 59 |
| Mental health [112]. | 52 |

Do you believe that the care-planning process, if properly designed and implemented, could produce any of the benefits listed below?

% of respondents saying "Yes".

[Number of groups providing an opinion in this category]



Care plans—design and implementation

This survey indicates that, by July 2009, only a minority of patients with a long-term condition were in a possession of, have asked for, or have been offered, a care plan.

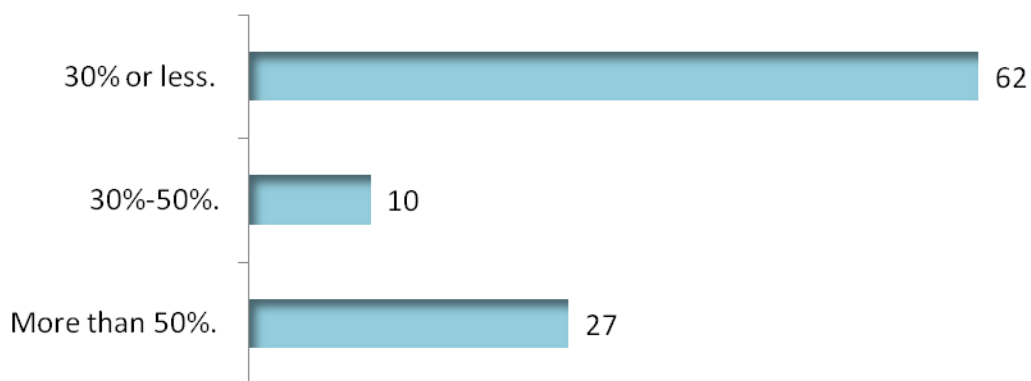
Given the current low level of implementation, the government seems unlikely to meet its target for care plans by June 2010.

- 62% of respondents say that just 30% or less of their members with a long-term condition have a care plan.
- Over 60% of respondents say that just 30% or less of their members with a long-term condition have either been offered or asked for a care plan.
- Nearly three quarters (76%) of the respondents think it “unlikely” or “highly unlikely” that the government will attain the goal of offering all people with a long-term condition a care plan by June 2010.

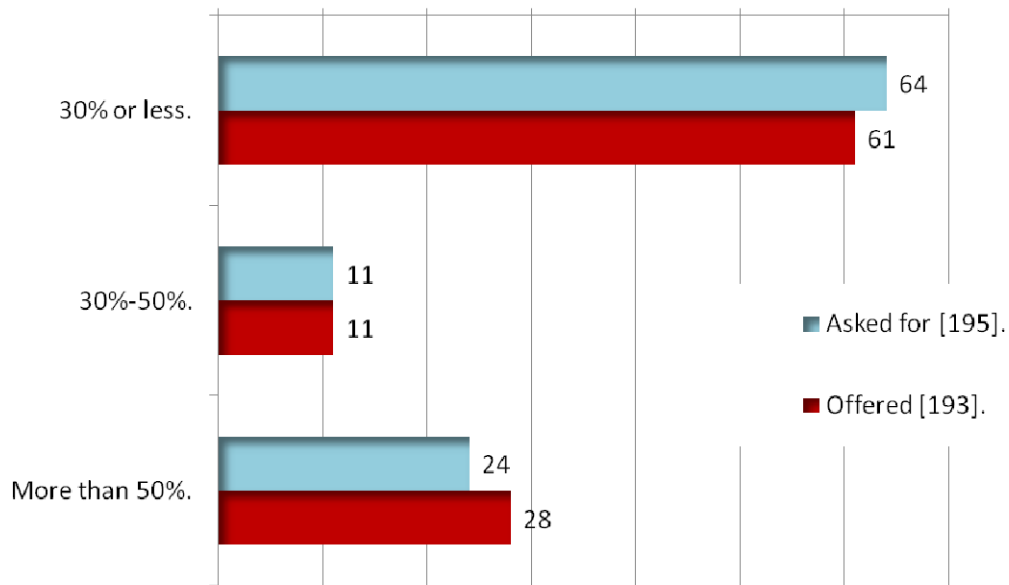
See chart below and on next page

Among the people with a long-term condition who are represented by your group, what percentage would you say currently have a care plan? % of responses, excluding those who do not know.

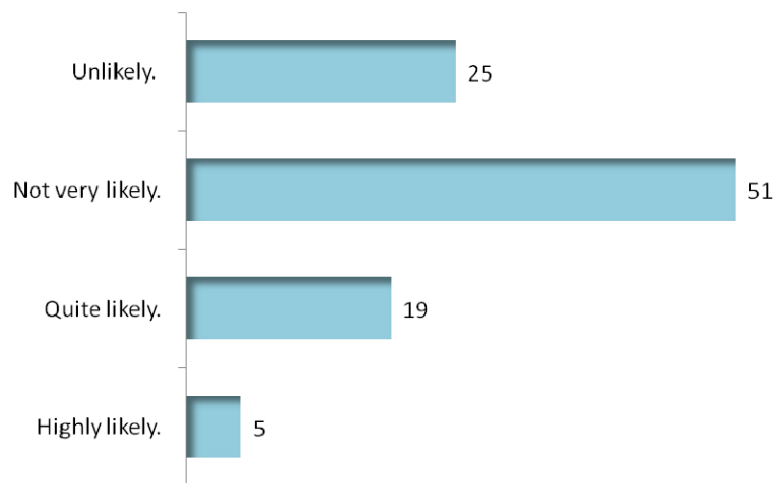
Number of groups providing an opinion = 249



Among the people with a long-term condition represented by your group, what percentage have asked for (or have been offered) a care plan?
% of responses, excluding those who do not know.
[Number of groups providing an opinion in this category]



The DoH expects everyone with a long-term condition to be offered a care plan by June 2010. How likely is that goal to be attained?
% of responses, excluding those who do not know.
Number of groups providing an opinion = 360



The survey finds that care plans, as they are instituted today, are only moderately effective (and, in some cases, ineffective) at achieving gains for patients.

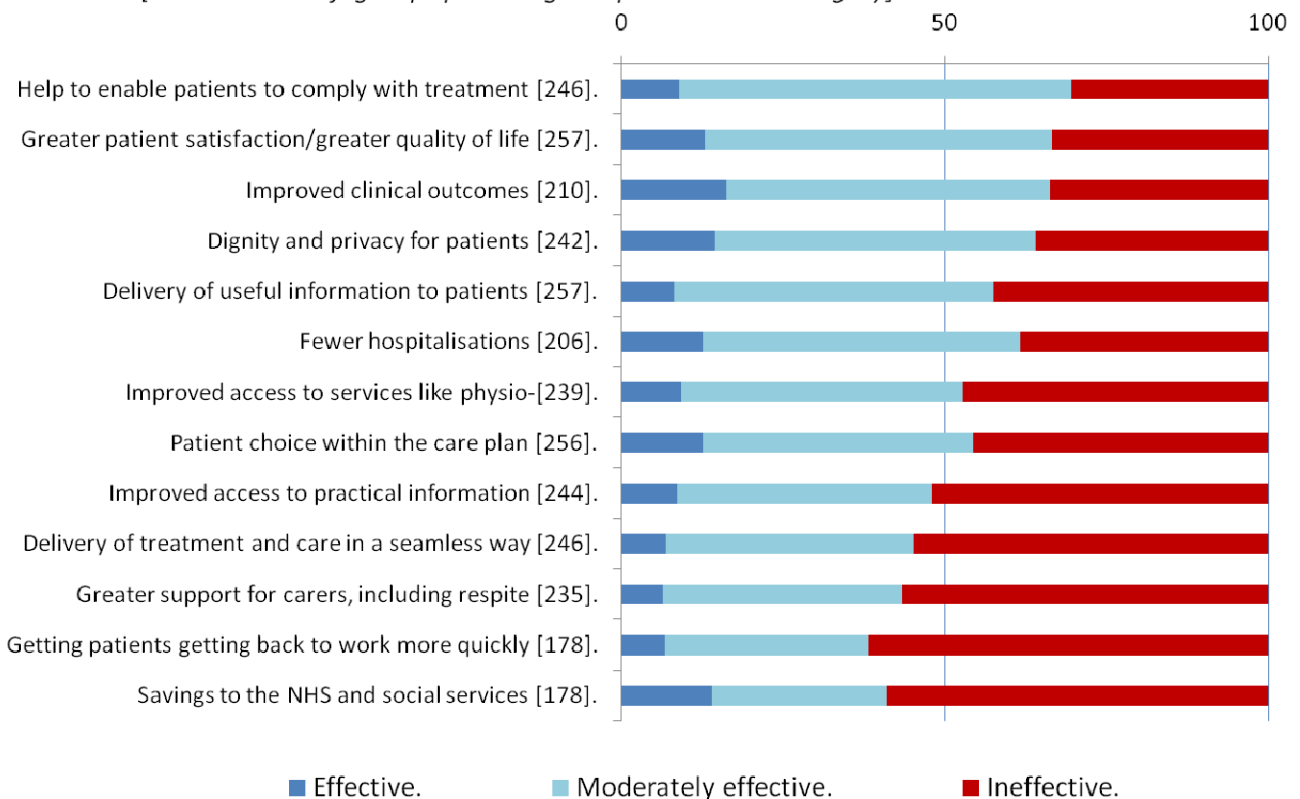
Although patient groups and the other voluntary organisations participating in the survey regard care plans as beneficial for patients, these plans—as they are currently practised—fall short of the mark in several key ways:

- Half or more of the respondents argue that care plans today are ineffective at improving access to practical information; at delivering treatment and care in a seamless way; and in providing greater support (including respite) for carers. Around 60% of the respondents report that these benefits would, however, come about if care plans were properly designed and implemented [see page 8].
- According to 70% of the respondents, the ideal two-top benefits that care plans can bring to patients are greater patient satisfaction (including improved quality of life) and the delivery of useful information [see page 8]. Only 13% and 8% of respondents respectively, though, feel that care plans, as currently put into operation, have achieved those goals.

In your opinion, how effective is care planning (as practised today) at bringing about the following benefits?

% of responses, excluding those who do not know.

[Total number of groups providing an opinion in this category]



The survey reveals that patients (or their carers) are rarely consulted in the design of their own care plans—thereby undermining the effectiveness of the plans.

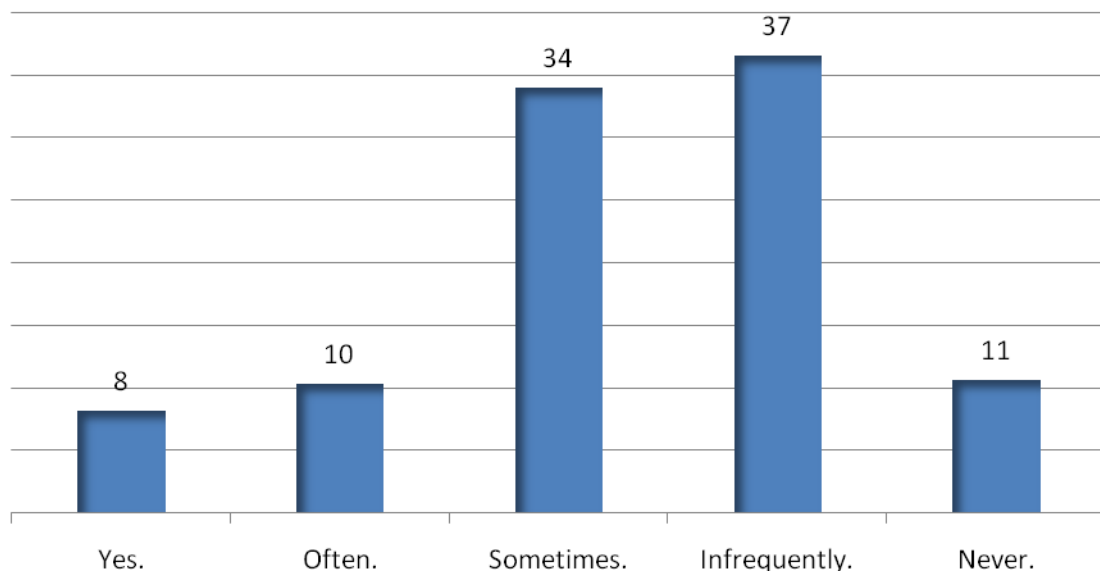
The government has stated that the design of individual care plans should involve patients and their representatives. However, just 18% of the respondent groups say that patients “are” or “are often” involved in the design of the care-planning process. A further 34% consider that patients are involved, but only “sometimes”. And as many as 48% believe that patient input happens “infrequently” or “never”.

According to one in five of the respondents, the main barrier to the implementation of effective care plans is that some healthcare professionals/agencies do not communicate adequately with patients [see table on the next page]. But, whatever the underlying causes of the inadequate levels of patient consultation, a significant number of survey respondents clearly believe that it undermines the effectiveness of care plans.

In your opinion, are patients sufficiently involved in the design of the care planning process?

% of responses , excluding those who do not know.

Number of groups providing an opinion = 317



What do you believe are the barriers to the implementation of effective care plans?*The top-five reasons provided, ranked according to numbers of mentions*

| Ranking | No. of mentions | Barriers to implementation |
|---------|-----------------|---|
| 1 | 101 | Some healthcare professionals lack the time to implement care plans/ too few healthcare professionals are available to run the care-planning process. |
| 2 | 80 | Some healthcare professionals lack knowledge of certain medical conditions, or lack empathy with aspects of patients' lives. |
| 3 | 69 | A lack of communication exists between some departments/agencies/healthcare professionals, and too many different types of professionals are involved in the care-planning process. |
| 4 | 65 | Some healthcare professionals/agencies do not communicate adequately with patients (patients lack knowledge/awareness of care plans). |
| 5 | 57 | A lack of funding and the costs of implementation prevent people from getting a care plan (matching personal care plans to what care is available is difficult, due to inadequate resources). |

The patient is left waiting for very long periods of time and feeling alone and worthless in this current system with no voice or say about what they need and what might help them better.

Care professionals too easily discount the skills, options, and experience that the service users may bring to the table, and seem crippled by the fear of identifying needs that they are unable to provide for.

As a patient with a long-term condition, I didn't even know these care plans existed.

Care plans—providing patient support

The survey finds that most patients (or their carers) are not provided the support they need to participate in care planning and implementation. When patients are offered support, the contributions they value most highly are from specialist and community nurses.

Only one fifth of the respondents state that patients are “always” or “often” provided with the support they need to contribute to the design and implementation of their care plans. Around 36% note that appropriate support is “sometimes” given. And, as many as 43% say that patients are “rarely” or “never” provided with the support needed to participate in care planning.

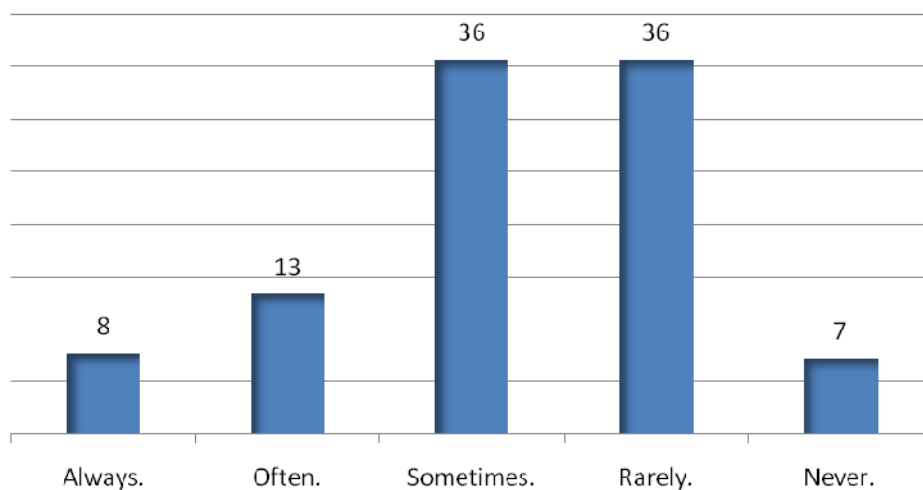
When patients do get support, it is specialist nurses (who have a more detailed knowledge of an individual condition, such as diabetes or cancer, than general nurses) and community nurses (such as district or psychiatric nurses) who are able to provide “a lot” or “some” support (mentioned by 76% and 67% of the respondents respectively)—more so than consultants or GPs.

Equally, when asked to specify the health professionals that patients would ideally like to work with to plan the care they need, 79% of survey participants emphasise specialist nurses, and 63% refer to community nurses. Support from social workers and allied professionals (such as dieticians or physiotherapists) is also suggested by the majority of respondents as preferable to that of consultants and GPs.

As far as you are aware, are patients provided with the appropriate support to help them contribute to the care planning process?

% of responses , excluding those who do not know.

Number of groups providing an opinion = 246



How much support do patients get from the following health professionals in the care planning process?

% of respondents saying "a lot/some" support, excluding those who do not know.

[Number of groups providing an opinion in this category]



With which health professionals would patients ideally like to work collaboratively to plan the care they need?

% of responses, excluding those who do not know.

[Number of groups providing an opinion in this category.]



Care plans—moving forward

Among the many recommendations offered by survey respondents, the most frequently cited is a call for better co-ordination among multidisciplinary teams of health professionals—and, notably, the designation of a named key worker as a care co-ordinator.

If you were to name just one change that could be made to improve the process of care planning, what would that change be?

The top-five reasons suggested, ranked according to numbers of mentions

| Ranking | No. of mentions | Changes required to improve care planning |
|---------|-----------------|---|
| 1 | 67 | Appropriate healthcare professionals should be available (often specialist nurses, but also other specialists, such as physiotherapist, psychologists, speech therapists). These multidisciplinary teams should communicate well with each other. And patients should be allocated a named key worker (care co-ordinator—sometimes described also as a single point of access). |
| 2 | 49 | Health professionals should communicate better/listen more to/spend more time with their patients, and have a lower caseload. |
| 3 | 42 | Healthcare professionals should be educated about the characteristics of certain conditions, about aspects of patients' lives, and about the care-planning process. |
| 4 | 23 | Information for patients should be better/more patient-friendly. |
| 5 | 27 | Patients should be involved in their own care-planning process, and be consulted as much as possible from the beginning (joint ownership). Care planning should be linked with initial diagnosis. |

I have noticed that you do not list third sector professionals at all as being involved in this process and yet we often play a crucial role. We often see patients on a more regular basis so can offer insights into their needs.

Timeliness: so often by the time a plan is agreed it is out of date, and implementation can also take years (eg supply/repair of wheelchairs, hoists, repeatedly delayed hospital admissions etc ad nauseam).

Appendix

The groups listed below wished to be named in this report as survey respondents.
Each organisation's name is spelled exactly as provided by the respondent themselves.

A

Access Association, South Central Region
ACT: Association for Children's Palliative Care
Action for Sick Children
ADHD Adult & Adolescent Support Network
Age Concern Boston & South Holland
Age Concern Cambridgeshire
Age Concern Swanscombe & Greenhithe
Age Concern Wakefield District
Allergy UK
Alzheimers Society
Harrow and Hillingdon Branch
Arthritis Care
AS IF...' (Alcohol Services Independent Forum)
Asian Family Counselling Service
Association of Young People with ME (AYME)

B

B&D Access Group
BackCare-Chelmsford Branch
Behcets Syndrome Society
BENCARE Complementary Health and Fitness
BESIDE- Mental Health Community Project
Bipolar4all
Blackpool Carers Centre
Body & Soul
Bolton Fibromyalgia Support Group
Borders Asperger & Autism Group Support
(BAAGS)
Bosom Pals MK
Brain and Spine Foundation
Brainstrust
Breast Cancer Haven
Brent Heart of Gold Support Group
Bristol lung cancer support group
British Polio Fellowship

C

CancerCare
North Lancashire and South Lakeland
Canterbury and Coastal Rethink
Carers' Support Group
Carers Lewisham
Carlisle ME/CFS Support Group
Cavernoma Alliance UK
Chiropractic Patients Association
CLASH: Community Leicester Arthritis Self Help
Cleveland Branch of
Motor Neurone Disease Association
CLIC Sargent
Coalition of Ankylosing Spondylitis Patients

Colchester Community Voluntary Services
Consumer Liaison Group NCRI
Cornwall and Isles of
Scilly Community Health Services
Crossroads - St Helens, Halton, Wigan & Leigh
Crusaid
Cumbria Crossroads Caring for Carers

D

Dales Heart Cardiac Support Group
Darlington Cardiomyopathy Self-support group
Darlington LINK
Deafness Support Network
Disability Action in the Borough of Barnet
DisAbility Matters
Dorset ADHD Support Group
Dudley PCT's
Dudley RA Support Group

E

East Dorset and New Forest MND
East Lindsey Heart Support Group
East of England Ambulance Service NHS Trust
East Sussex Community
Information Service (ESCIS)
Eastbourne and Wealden
Multiple Sclerosis Society
Ecas
ECHO (Evelina Children's Heart Organisation)
Epilepsy Action
Epilepsy Action, Guildford Support Group
Epilepsy HERE
Essex Coalition of Disabled People (ECDP)
Expect Health
EXTEND

F

Free the Child
Fibrohouse Northern
Fibrolincs Fibromyalgia Support Group
Fibromyalgia Association Castleford
Fibromyalgia Association UK
FIH
Friendship House Trust, Minster

G

Gear Projects.
Gender Identity
Research and Education Society
Gloucestershire Lifestyles

Gloucestershire MS Therapy Centre
Greater London Forum for Older People
Greater Midlands Cancer Network
User Partnership
GUCH Patients Association
Guilford Support Group of Epilepsy Action

H

Hambleton over Fifties Forum
/ Richmondshire Senior Forum
Harrow Rethink Support Group
Harrow Support Group - Coeliac UK
Head and Neck/Tracheostomy/
Laryngectomy/Support Group
Headway Plymouth
Headway Shropshire
Highfield Health Promotion Group
Horsham branch of MS Society
Huntington's Disease Association

I

Independent Living Community Support
Independent Living Partnership Ltd
Infertility Network UK
Involving Essex
Ipswich Blind Society
Ipswich fibromyalgia group

K

Kent & Medway Networks Ltd
Kent LINK
kites children & young peoples bereavement
service at St Josephs Hospice

L

Leicestershire Leicester and Rutland Headway
Leukaemia CARE
Lincolnshire Autistic Society
Lincolnshire Kidney Patient Association
Lincolnshire MS Therapy Centre
Lincolnshire Post Polio Network
Linking Voices
Liz Else
Luton and District Breathe Easy Group

M

M.S. Society Banbury and District Branch.
Manchester Alliance for Community Care
ME Staffordshire Support

Appendix (continued)

Merton Branch MS Society
Milton Keynes ICD Support Group
Mind drop in centre
Mind in Brighton & Hove
Mind in Croydon

Motor Neurone Disease Association
Mouth Cancer Foundation
MS Aylesbury Ducklings (Bucks branch of
Multiple Sclerosis Society)

MS Society
MS Society - West Herts Branch
MS Society Amersham and Chesham Branch
MS Society. Telford&District Branch
Multiple Sclerosis Society North Surrey Branch
Multiple Sclerosis Tamworth & Lichfield

N

NAS North Yorkshire Central Branch
NASS
National Ankylosing Spondylitis Society
Crewe Branch
National Association of Laryngectomee Clubs
National Long Term Survivors Group (HIV)
National Network for Palliative Care
of People with Learning Disabilities
National Osteoporosis Society
New Speakers Club Manchester
Newark & District Multiple Sclerosis I
nformation & Support Centre
Newham Carers Network
NHS Kirklees
North East Laryngectomes Association
North Staffordshire Laryngectomee
Support Group
North Staffs Prostate Cancer Support Group
North Staffs Users Group
Northampton Breast Cancer Support Group

O

OUCH UK

P

PACE
Paget's Association
Papworth Hospital Pulmonary Hypertension
Support Group
PAPYRUS Prevention of Young Suicide
PeopleFirst of Norfolk Great Yarmouth
Poole & Bournemouth Transverse Myelitis
Support Group
Poole ICD support group
Poole Mental Health Forum
Prader-Willi Syndrome Association (UK)

Preston fibromyalgia support group
Prestonfield Neighbourhood Project
Prostate Cancer Support Federation

R

Redbridge Breast Friends
Responding Together Against Domestic Abuse
Restart Rotherham
Roy Castle Lung Cancer Support Group
Birmingham
Royal free hospital trust
RSI Action

S

S.P.L.A.Sh - Supporting People
Linked by ADHD in Sheffield
Sainsbury Centre for Mental Health
Scarborough Disablement Action Group
Scunthorpe & District Mind
Sense
Sheffield Fibromyalgia Self Help Group
Shrewsbury and Mid Wales
Laryngectomee Club
Shrewsbury Fibromyalgia Support Group
Shropshire ME Group
SMUG
Socialist Health Association
South Yorkshire Eating Disorders Association
Southampton Centre for Independent Living
Southport Fibromyalgia Support
St John Ambulance Northumbria
St John's Social Activities
and Sports Group
Steps
STEPS Charity Worldwide
Suffolk Mental Health Partnership Trust
Swale ASD Support group

T

Tall Persons Club GB and Ireland
Teesside Hospice Care Foundation,
Middlesbrough
Terrence Higgins Trust
The Asperger Training Company
The Cara Trust
The Forum Link Project
The Klinefelter Organisation
The Lymphoedema Support Network
The Mental Health Providers Forum
The OCD Centre
The Pancreatitis Supporters Network
The Prostate Cancer Charity
The Roy Castle Lung Cancer Foundation
The Transverse Myelitis Association

Thyroid UK
TOP UK
Torbay Prostate Support Association (TPSA)
Transverse Myelitis Society
Transverse Myelitis Society

U

U.K. T.M. Society
United Kingdom Primary
Immunodeficiency Association
Urostomy Association

V


Voluntary Action South Leicestershire

Planning Care—the Patients' Perspective

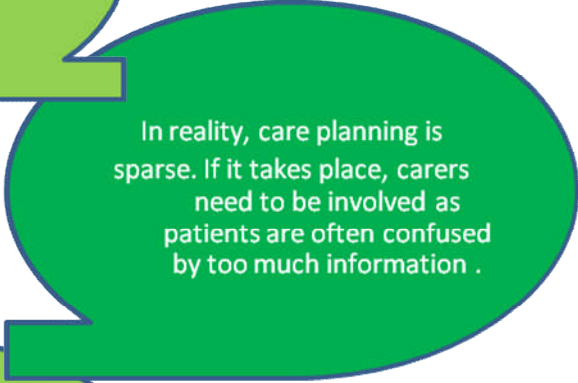
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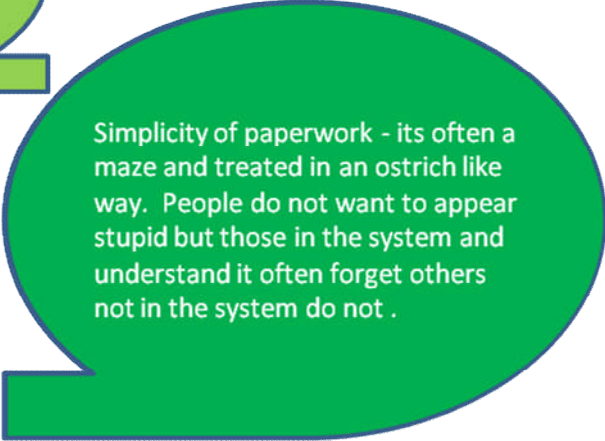
I only know of about 5 or 6 patients with ME in Staffordshire who have a care plan.



In reality, care planning is sparse. If it takes place, carers need to be involved as patients are often confused by too much information .



Some patients are unable to draw attention to their needs, and so go neglected.



Simplicity of paperwork - its often a maze and treated in an ostrich like way. People do not want to appear stupid but those in the system and understand it often forget others not in the system do not .