INFORMATION PROVISION FOR PEOPLE WITH MULTIPLE SCLEROSIS

A theory of change and outcomes measurement framework approach

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CONTENTS

EXECUTIVE SUMMARY

This report explores how providing information to people with multiple sclerosis (PwMS) can improve their lives. It describes the process NPC undertook with the MS Society, MS Trust and other stakeholders to develop a theory of change for the outcomes of information provision. In the following pages, we outline the measurement framework used to prioritise these key outcomes, and provide practical tools for measuring whether those outcomes are being achieved. We also present examples of user journeys, which depict the role information could play in the lives of individual PwMS by both answering their questions and empowering them.

The context for information provision

Our healthcare system is moving towards a person-centred model in which information is vital. For people to be able to take a more central role in their healthcare they need access to trustworthy information on a range of topics which they can use to make decisions.

PwMS have complex information needs. MS is a chronic, degenerative neurological condition that affects an estimated 100,000 people in the UK, with a highly individualised pathway. The information needs of PwMS may vary according to a range of factors including: types of MS, disease progression, symptoms, economic and social circumstances, age, ethnicity, gender and gender identity.

We lack evidence on the outcomes of providing information to PwMS. There is reliable evidence that PwMS become more knowledgeable about their condition as a result of receiving information. However there is little evidence to confirm more substantive benefits directly attributed to providing information to PwMS, or to particular models of service delivery.

Information should be distinguished from advice or advocacy. Information is facts and data of interest to a particular person or group of people. Advice, on the other hand, is direction on a particular course of action that needs to be undertaken in order to realise a need or access a service. Meanwhile, advocacy is the provision of support and encouragement, or the representation of an individual’s or group’s views and rights.

There are obstacles to providing information to PwMS. Providing information to PwMS faces strategic challenges, each of which calls for a strategic response. These responses include determining how to re-engage PwMS who are disengaged from information provision, how to minimise demands on the time of health care professionals, how to respond to the inequality of care across the country, how to tackle misleading information, and how to encourage the flow of information between PwMS.

We should be sensitive to the social context of information provision. Key contextual factors include:

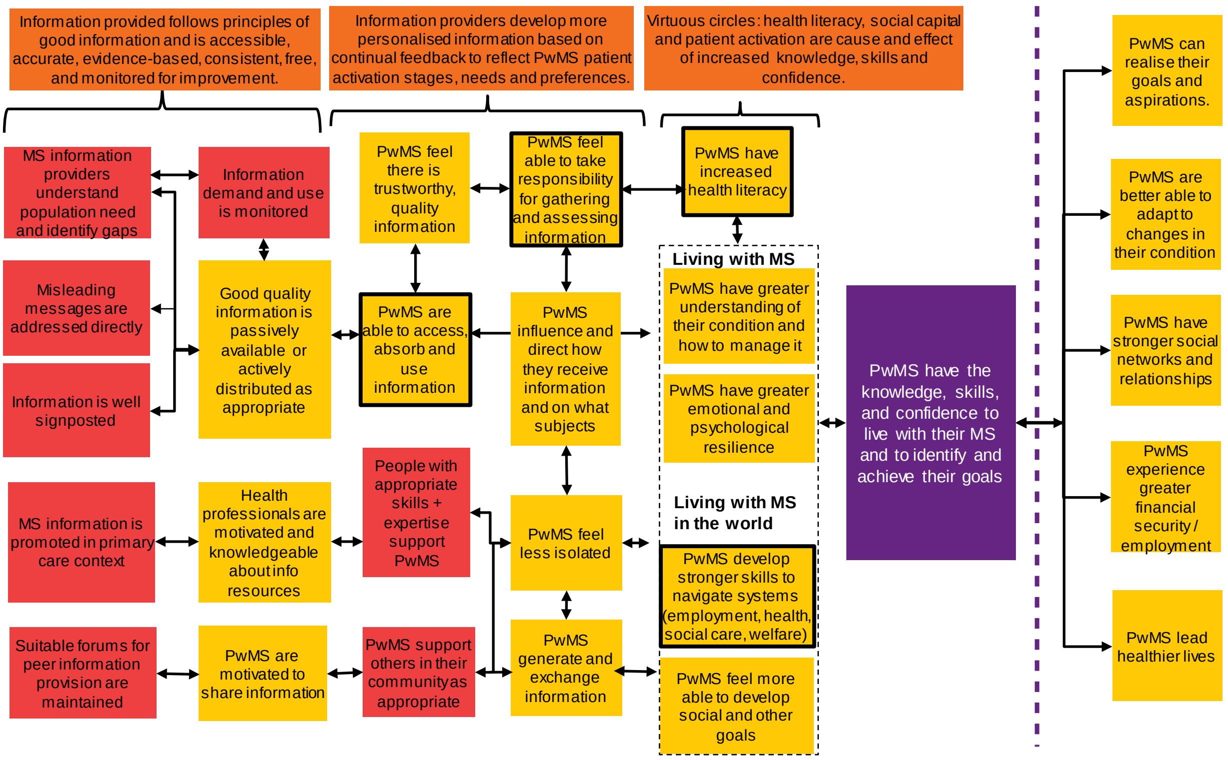
- Some PwMS are currently excluded or disengaged from information provision.
- There are natural peer groups of PwMS.
- Some information issues are sensitive, such as bowel or sexual function.
- Demographic factors play an important role and some ethnic groups may experience different levels of stigma attached to MS.
- PwMS experience different types of anxiety related to their condition.

We can identify principles of good information provision. Information should be appropriate to beneficiary needs—it should be interactive, accessible, timely, and engaging. Information should also be accurate, evidence-based, consistent, comprehensive, and reliable. Finally, information should tackle conspiracy theories or falsehoods directly, and should be grounded in peer provision where appropriate.

Theory of change

A theory of change process was used to map outcomes of information provision. A theory of change is a model of how social change is achieved in a specific context. Following discussions at a stakeholder workshop, NPC developed a theory of change which models the outcomes of providing information to PwMS (reproduced over a full page in the appendix):

Theory of change for providing information for people with multiple sclerosis



Key to the diagram

🟪 Ultimate goal

🟥 Activities

🟨 Intermediate outcomes

🟨 Priority outcomes

🟧 Enabling factors

← Direct link

⬚ Combined impact (ie, applies to all outcomes inside the dotted box)

┆ Line of accountability: outcomes to the right of the line may be beyond scope but are still sought

The theory of change aims to accommodate the following points:

The final goal of information provision is to empower PwMS to live autonomously. The theory of change shows how the MS sector helps support PwMS through the provision of information. It suggests the final goal of the sector's activities is: *PwMS have the knowledge, skills, and confidence to live with their MS and to identify and achieve their goals*. All the activities and intermediate outcomes shown contribute to the achievement of this goal.

We need to take patient activation into account. 'Patient activation' is a behavioural concept that refers to how involved a patient is in their care. A higher level of activation means a patient is better able to understand their role in the care process and feels more capable of meeting that role. Patient activation is therefore related to individuals' use and engagement with information.

Living with MS and living with MS in the world are different but related. Living with MS refers to PwMS having greater understanding of their condition and how to manage it. Living with MS in the world instead relates to how PwMS learn to navigate social systems that may support (or hinder) PwMS. Both are key outcomes of information provision

There are outcomes of information beyond the stated final goal. The test of the success of information provision is whether it facilitates PwMS in working towards their life goals, rather than ensuring that those life goals will be realised in every case. It is important to be realistic about what good information can and cannot achieve. In addition, achieving the goals of an information provision theory of change is dependent on a much larger system, which includes a range of healthcare provision and other actors.

There are virtuous circles within the provision and use of information. Health literacy, social capital and patient activation are a cause and effect of increased knowledge, skills and confidence. In other words, seeking, using and responding to information is a process, and the more information PwMS interact with, the more they will grow in the confidence required to drive the demand and generation of relevant content.

Outcomes measurement framework

It is important to prioritise outcomes. A priority outcome is one that matters most to the topic at hand, is particularly important to achieve, and may be within the control of an organisation. The priority outcomes for measurement of information provision in this instance are:

- PwMS are more able to access, absorb and use information.
- PwMS develop stronger skills to navigate systems (employment, health, social care, welfare).
- PwMS feel able to take responsibility for gathering and assessing information.

Indicators and metrics for each outcome can then be selected. This enables organisations providing information to PwMS to measure their impact and to use common measures where possible.

There are several stages to implementing an outcomes measurement framework. Putting a measurement framework into practice entails gathering insight into users, taking a proportionate approach to information collection and building on existing data collection options. We recommended administering a short universal survey, qualitative data from a small sample, and the continuous use of a user panel.

User journeys

User journeys help illustrate the contexts for realising outcomes and are extremely useful for mapping interaction with services. They chart the various interactions between an individual and an organisation, reflecting on the outcomes achieved along the way. In this case, they help show that information should not only be obtained by PwMS but also used and increasingly driven by them too. We developed two user journeys. One depicts a journey through MS diagnosis, and the other a journey through information usage.

Shared measurement

Shared measurement is a long term sector goal. It involves charities working on a similar issue reaching agreement over what to measure in judging the impact of their work. The first step is making a commitment to impact measurement and the second is identifying shared outcomes to work towards. Charities can then choose to use the same metrics and, finally, to work together in delivering outcomes.

Conclusion

Working towards common outcomes is a key step in the sector's journey. A developing information strategy for the sector needs to account for the wider context of health charities in a changing healthcare system, the developing research base and the importance of sector leadership. The set of outcomes introduced in this report should provide a firm, shared foundation from which to develop and improve services and impact.

INTRODUCTION

Framing the issue

Our healthcare system is moving towards a more person-centred model.[1] This new model aims to empower people to take a central role in their own healthcare. For people to feel in control of their health and their treatment, it is vital that they have access to trustworthy information on a wide range of topics. They also need to be able to use that information when making decisions.

Multiple sclerosis (MS) is a chronic, degenerative neurological condition that affects an estimated 100,000 people in the UK, with roughly four times as many women as men affected.[2] The MS pathway is highly individualised, as symptoms can fluctuate and vary significantly, both between individuals and for each individual at different times in their lives. MS takes several forms (including relapsing remitting MS, primary progressive MS, and secondary progressive MS) and may be accompanied by other physical or mental health conditions. Symptoms associated with MS include: bowel and/or urinary problems, cognitive dysfunction, fatigue, mobility impairment or paralysis, pain, problems with speech and/or motor coordination, spasms, and visual impairment.[3]

People with MS (PwMS) are not, therefore, a homogeneous group. Given MS is a long-term condition of an individualised nature, understanding and living with the condition can be complex and therefore the information needs of people living with MS are complex too. These needs will vary depending on types of MS, disease progression, and symptoms. Information needs may also vary according to economic and social circumstances, age, ethnicity and nationality, gender and gender identity. Information should then be provided that reflects these needs, while enabling individuals to take a stronger role in using information to support their decisions.

Access to reliable information about their condition, and about the healthcare and social systems with which they interact, could improve the lives of every PwMS. The MS Society commissioned NPC to explore how best to make this happen. By thinking through the role of information in the lives of PwMS the work aimed to suggest how PwMS can use information to help them understand and manage their MS. The potential payoffs include PwMS becoming more knowledgeable, more confident, less isolated and more autonomous in living their lives. Given what could be achieved, this is an immensely exciting and important project.

What we know

There is a current lack of robust evidence on outcomes that can be directly attributed to providing information to PwMS, or to particular models of service delivery.[4,5] There is reliable evidence that PwMS become more knowledgeable about their condition as a result of receiving information, but little evidence to confirm more substantive benefits.[6] Although we do not have evidence about what it would be like for PwMS to have *no* information about their condition, a recent systematic qualitative review of studies reporting patients' experiences of health-care services in the UK found that a *lack* of information about MS leads to a range of negative consequences including dissatisfaction with health-care services and to emotional states such as anxiety and fear.[7]

There are some studies, though, that have started to explore the link between information uptake by PwMS and other outcomes. While these are not comprehensive and generally have a low quality of evidence, they give us some reason to think the following:

- Information at the right times leads to decreased anxiety, increased empowerment and increased symptom management among PwMS.[8]

- Information on drugs and new treatments leads to decreased feelings of helplessness and hopelessness among PwMS.[9]
- Information on research leads to an increased ability to share decisions with healthcare teams.[10,11]

Aims and objectives of the project

A primary aim of this project is to think through the role of information in the lives of PwMS. Central to this is the question of what the main goal is in providing information for someone with MS. The theory of change process is designed to formalise thinking on this question, and (as we explain below) we draw on the expertise and experience of a range of stakeholders in developing the theory of change. It is important that the model presented here is taken as the first step in a collaborative process of developing sector-wide thinking about information use among PwMS.

Another core aim of this project is to think about how we can measure the success of information sharing activities. The model we introduce here focuses on measuring outcomes—defining the intended changes that result from those activities, and specifying the data needed to show those results. This enables information providers to improve those activities, and to more effectively support information use among PwMS.

A more ambitious aim of this project is to assist thinking about impact measurement within the MS sector as a whole. When a group of organisations carry out diverse activities but work towards a shared goal, they can use common outcomes and measures to share results and collectively improve the evidence and practice. In the final section of this report we trace out some key stages of this journey.

Aims of this report

This report aims to:

- present a model of how information can be used by PwMS (the theory of change);
- outline a framework that can be used to measure the outcomes of activities that support information flow to and among PwMS (the outcomes measurement framework); and,
- sketch out what a journey to impact measurement could look like for the MS sector.

THEORY OF CHANGE

Introduction

What is a theory of change?

A theory of change is a model of how social change is achieved in a specific context. It explains how the activities an organisation carries out are logically linked to the final goal of that organisation, demonstrating how day-to-day tasks are intended to further its mission.

In this report, we talk about theory of change both as a model and a process. The model consists of a diagram and an explanatory narrative, which we set out below. But the process of creating a theory of change is also important. It allows people working in a sector to come together and discuss the context, challenges, and goals of what they do. In this way, it is an invaluable opportunity to make explicit things that may be ‘taken for granted’ in a sector, and build a shared understanding.

Theory of change thinking is usually the first step in most hierarchies of evidence quality; it is Level 1 on NESTA’s Standards of Evidence for Impact Investing, for example.[12] This is because a theory of change describes logically the difference an organisation aims to make, why it matters, and why we have good reason to think that its activities might bring about its organisational goals. Later steps then involve finding evidence that the links between activity and outcome described in the theory of change are, in fact, realised in real life.

The process we followed

The theory of change presented here is the outcome of a workshop facilitated by NPC and held on 2 December 2015. Attendees at the workshop included MS Society staff, MS Trust staff, an MS Society helpline volunteer, a neurologist from the Association of British Neurologists (ABN), and two specialist nurses from the UK MS Specialist Nurses Association (UKMSSNA). Two of the attendees were PwMS. A full list of workshop attendees is included at the end of this report. Although it was not possible for the workshop to be fully representative of everyone affected by MS and working in the MS sector, the aim was to get a wide range of voices and to bring a diverse set of perspectives to the issue of how information provision can help PwMS.

The development of the theory of change was intended to be as collaborative as possible. The broad steps of the process were as follows:

- NPC summarised some recent research on information provision and outlined the aims of the theory of change process;
- there was an open discussion of what the goal of provision and use of information among PwMS could be; and
- there were more focused discussions on how the intermediate outcomes of the activities of information providers and PwMS linked to the final goal.

NPC then worked to formalise the discussions of the workshop day, taking in feedback from workshop attendees to develop the theory of change diagram and narrative.

Context

Information—facts and data of interest to a particular person or group of people—can be distinguished from both advice and advocacy. Advice is direction on a particular course of action that needs to be undertaken in order to realise a need or access a service. Advocacy, on the other hand, is the provision of support and encouragement, or the representation of an individual's or group's views and rights. In this theory of change we will focus specifically on the provision of *information*.

The theory of change should be understood in the context of **strategic obstacles** for MS information providers, the **individual circumstances of PwMS**, and a **principles of good information provision**.

Strategic obstacles and solutions

A number of strategic obstacles currently stand in the way of 'successful' information provision to PwMS, some of the most challenging of which are summarised in the table below. These issues are primarily stated from the perspective of information providers and PwMS who are highly engaged in the production and use of information.

Strategic obstacle	Possible solution(s)
Some PwMS are disengaged (such as those receiving a diagnosis many years ago), and might be difficult to re-engage	Identify 'touchpoints' at which up-to-date information can be provided, such as an annual review More systematic monitoring of information uptake to prevent disengagement
Demands on health professionals' time are high, particularly within the wider context of inequality of care across the country	Augment advice from neurologists with peer support groups facilitated by MS nurses MS support groups can then address different demands, such as working with MS or issues with MS in young families
Many PwMS do not know what information they need or how they would benefit from it	Interaction between peers and professionals could help build an evolving picture of different information needs
Misleading information exists on the cause or cure of MS *How to encourage the flow of information between PwMS on online social networks, while stemming any misinformation that could also circulate*	Misleading and pernicious theories should be tackled proactively by putting the absence of evidence in perspective A 'shared platform' for neurologists and PwMS would allow both groups to speak in 'one voice' Providers curate quality information and are explicit and transparent about their supporting evidence

Individual circumstances of PwMS

Although MS is a condition with highly individualised pathways, with respect to information provision there groups or clusters of beneficiaries (as in PwMS) with similar situations.

- **There are PwMS who are currently excluded from information provision.** Those unable to access information are a key beneficiary group for better provision. Those who received their diagnosis many years ago may not know where to find information, while others may have reduced cognitive skills as a result of their MS. These groups may be operating with out-of-date information from professionals whose outlook might now be considered overly pessimistic. It is important to consider under what circumstances information would be more accessible to those groups, for instance to raise awareness or address visual or cognitive issues. Alternatively, if direct access is impaired, looking at routes of access for family or carers.

- **There are PwMS who are currently disengaged from information provision.** Those who received their diagnosis many years ago may not feel there is anything relevant to them, while those with negative experiences of health provision may be sceptical of resources. This is a key group to seek to appeal to and to re-engage.
- **Health literacy drives the ability for PwMS to judge information quality themselves.** The immediate goal of information provision might be to meet PwMS ‘where they are’ in terms of the complexity of information, while the eventual goal might be to work on and build up the health literacy of PwMS so they are better able to obtain, process, and use information. Health literacy refers to 'people having the appropriate skills, knowledge, understanding and confidence to access, understand, evaluate, use and navigate health and social care information and services'.[13] Importantly, it can be differentiated from the concept of patient activation that we discuss below since it refers more to the use of information than the engagement in care.
- **There are ‘natural peer groups’ of PwMS.** In social and support forums, the peer group someone with MS identifies with will depend on more than their age, and it is important to recognise that different settings exist for information provision and exchange.
- **There is a geographical inequality of care for MS in the UK.**[14] This is a key context of information provision.
- **Different ethnic communities might experience different levels of stigma attached to MS.** MS is most common in people whose ancestors are northern European. However, people of many ethnic backgrounds are affected by MS. Information provision strategies should be sensitive to this context.
- **Digital exclusion is a ‘live’ problem.** Not everyone is online—additional channels of information provision should be considered.
- **Information should be tailored for ‘sensitive’ issues.** Certain issues, such as bowel or sexual function, might be best met through comprehensive online information rather than face-to-face communication.
- **Some demographic factors will need to be taken into account.** For instance, younger PwMS might typically have better access to online information.
- **PwMS experience different types of anxiety relating to their MS.** Orientation anxiety (‘what will happen?’) is best addressed by a lot of information about the entire course of MS at point of diagnosis. Meanwhile, performance anxiety (‘how will I cope?’) is best tackled by practical strategies. Acceptance anxiety (‘what will others think?’) requires personal stories and narratives.

Principles of good information provision

There are a number of principles of good practice of information provision, some of which are specific to MS and some of which also apply to other health fields.

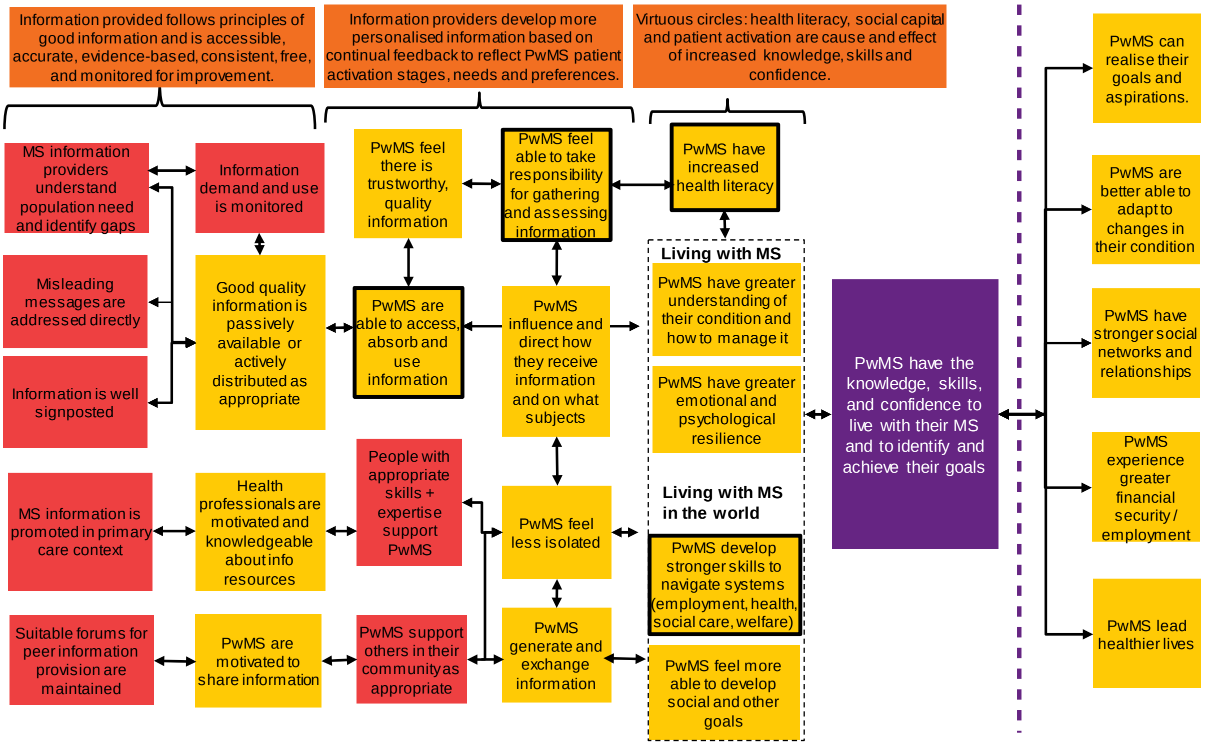
Principle of good information provision	What this could mean for information about MS
Information should be appropriate to beneficiary needs	*Interactivity:* information should be tested with PwMS and communicated in a way that facilitates feedback *Accessibility:* different levels of cognitive ability should be catered for; information is available in a variety of locations, and outreach provision should be considered *Timeliness:* information should be provided at the right time, with respect to the development of MS *Engaging:* it should be a specific goal to re-engage PwMS who have disengaged from information
Information should be of a high quality	*Accurate and evidence-based*: information should be based on current research on MS *Consistent and comprehensive:* there should be no omissions or contradictions between different sources; if there a genuine debate or disagreement, all well-evidenced, this should be communicated honestly *Reliable:* the objective quality of information should be designed to foster trust in it
Information should support the development of beneficiaries' health literacy	*Critical*: 'conspiracy' theories should be acknowledged and tackled directly
An element of peer provision should be actively fostered	*Social*: where appropriate, PwMS should be able to comment on information and recommend it to their peers *Empowering*: concerns about moderating forums notwithstanding, the peer provision of information should be recognised as empowering PwMS to think about their MS and share experiences
Information should be freely provided and independent from the interests of any group pushing their own agenda or theory	*Free:* information should be freely provided, both in the sense of being monetarily costless to obtain and being easy to acquire for PwMS

The theory of change diagram

The theory of change diagram is a simple visual that helps communicate the aims and work of the MS sector as a whole in providing information for PwMS.

Figure 1: Theory of change for providing information for people with multiple sclerosis

A full page version of this diagram is provided in the Appendix of the report.



Key to the diagram

🟪 Ultimate goal

🟥 Activities

🟨 Intermediate outcomes

🟨 Priority outcomes

🟧 Enabling factors

← Direct link

☐ Combined impact (ie, applies to all outcomes inside the dotted box)

┆ Line of accountability: outcomes to the right of the line may be beyond scope but are still sought

The theory of change narrative

To elaborate on the theory of change diagram, we provide some more information about the outcomes depicted, how they were chosen, and, in some cases, why the wording used was felt to be so important. This narrative provides further description of some parts of the theory of change and is intended to be read in conjunction with the diagram.

Final goal

This theory of change diagram shows how the MS sector helps support PwMS through the provision of information. It puts forward the end goal of the sector's information activities as: *PwMS have the knowledge, skills, and confidence to live with their MS and to identify and achieve their goals*. This is shown at the far right of the diagram. The central notion of the final goal is that PwMS are *empowered* to live autonomously (as far as that is possible).

The ability of PwMS to use information is based on the patient activation model. Patient activation is a behavioural concept. It refers to how involved a patient is in their care and can be defined as 'an individual's knowledge, skill, and confidence for managing their health and health care'.[15] A higher level of activation means a patient who is better able to understand their role in the care process and who feels more capable of meeting that role.[16]

Initial activities and their outcomes

The theory of change begins with information providers (including MS charities) ensuring the following:

- MS information providers understand population need and identify gaps
- Misleading messages are addressed directly
- Information is well signposted
- MS information is promoted in primary care context
- Suitable forums for peer information are maintained

Assuming that information provided follows the principles of good information outlined above, these activities would achieve three initial outcomes:

- Good quality information is passively available or actively distributed as appropriate
- Health professionals are motivated and knowledgeable about information resources
- PwMS are motivated to share information

These outcomes may not happen simultaneously; PwMS may feel motivated to share information when they start to become active information seekers. In the theory of change diagram, the fact that all arrows point in both directions shows that the provision of information and the later use of that information are looped together.

Second stage activities

The theory of change diagram shows that a second stage of activities act on the initial outcomes listed in the previous section:

- Information demand and use is monitored
- People with appropriate skills and expertise support PwMS
- PwMS support others in their community as appropriate

Importantly, these second stage activities also build towards the final goal of information provision. They operate as feedback loops, in which PwMS play an increasingly central role in driving the type of information content generated. Specifically, information providers respond to user demand for content that reflects their interest.

Healthcare professionals are sought out by PwMS when they are relevant to them. PwMS contribute and exchange knowledge with one another, and thus contribute to the network of information production and exchange.

First stage outcomes of good quality information

Good quality information has a number of important outcomes, which the theory of change diagram shows as forming an outcomes chain:

- PwMS are able to access, absorb and use information
- PwMS feel there is trustworthy, quality information
- PwMS feel able to take responsibility for gathering and assessing information
- PwMS have increased health literacy

It is key that PwMS **trust** the information that they receive, and so feel increasingly able to gather information themselves. In the long term, this feeling of increased autonomy in the field of information is closely linked to increased health literacy. Good quality information also directly improves **knowledge** (both of MS and of acting in the world with MS), enables the development of **skills**, and increases **confidence**. As the theory of change diagram illustrates there are a number of virtuous circles here, such that increased health literacy, patient activation and social capital are effects of increased knowledge, skills, and confidence—and also contribute to PwMS developing these ‘personal resources’.

Second stage outcomes of good quality information provision

- PwMS influence and direct how they receive information and on what subjects (demand)
- PwMS generate and exchange information (supply)

The provision of information is not one-way, though the initial steps are taken by providers within the sector. The next stage in development involves co-production among users. PwMS gain confidence in appraising the quality of information and can navigate to content that is relevant to them when they need it. PwMS demand information: they influence and direct how they receive information and on what subjects. PwMS therefore have a role in shaping the format, channel and content of information. Feedback and interaction with providers gives them a voice to specify what content is useful, which informs future provision. This represents a continuous feedback loop of interaction between user and provider.

PwMS generate knowledge and insight themselves as patient experts, which contributes to information sources. They also directly exchange information with each other.

As they engage with information providers and on peer support forums, they contribute and swap information, building a network of information exchange and support. PwMS thus drive a generation of more relevant content, and participate in the production of information. As discussed in ‘strategic challenges’, there is a role for experts to play. This can include formal medical expertise or PwMS themselves monitoring and moderating, to avoid the circulation of misinformation.

Outcomes of support in information provision and collection

Receiving support from those with the relevant skills or experience has the outcome of making PwMS feel less isolated, and, in turn, creating feelings of solidarity and belonging in the community. This then has the outcome of increased confidence among PwMS.

Living with MS and living with MS in the world

Directly before the final goal are the two pairs of outcomes that link directly to the personal changes that information can help PwMS to achieve. We divide these outcomes into ‘living with MS’ and ‘living with MS in the world’. The former outcomes relate to how PwMS live with their MS, in terms of understanding their condition, managing their symptoms and responding emotionally to changes in their lives. These outcomes are that PwMS have greater understanding of their condition and how to manage it and that PwMS have greater emotional and psychological resilience. The latter instead relate to how PwMS learn to navigate social systems that may support (or hinder) PwMS. This would include becoming a more confident advocate of their own health needs or employment rights. These outcomes are stated in the theory of change diagram as: PwMS develop stronger skills to navigate systems (employment, health, social care, welfare), and PwMS feel more able to develop social and other goals.

Outcomes beyond the final goal

Increased knowledge, skills, and confidence enable PwMS to live with their MS and to navigate social systems, such as employment. They also allow PwMS to specify and work towards aims beyond the final goal, although the provision of information alone cannot guarantee this will occur in practice. The (purple dotted) ‘line of accountability’ shows this in the theory of change diagram: the test of the success of information provision is whether it facilitates PwMS in working towards their life goals, rather than ensuring that those life goals will be realised in every case. This is an important clarification, since it is important to be realistic about what good information can and cannot achieve. In addition, achieving the goals of an information provision theory of change is dependent on a much larger system, which includes a range of healthcare and other actors. Nevertheless, the final goal of information provision is to equip PwMS with tools, and a feeling of empowerment to use those tools in the ways that work best for them.

It is possible that each of these outcomes beyond the final goal (and beyond the line of accountability for an MS information provider) could have its own theory of change. If this were to be the case, then information provision would be an important strand, but not the whole picture.

Enabling factors

Depicted across the top of the diagram are the enabling factors that the theory of change depends upon. The first enabling factor is that information provided follows principles of good information and is accessible, accurate, evidence-based, consistent, free, and monitored for improvement. For information to benefit PwMS in the way the theory of change assumes it will, it will have to meet these conditions. The second enabling factor is that information providers develop more personalised information based on continual feedback to reflect PwMS’ patient activation stages, needs, and preferences. It is key that information providers use information on the needs and segmentation of PwMS continually to improve their information offer.

The third enabling factor is that there are ‘virtuous circles’ within information provision and use: health literacy, social capital and patient activation are cause and effect of increased knowledge, skills and confidence. In other words, seeking, using and responding to information is a process, and the more information PwMS interact with, the more they will grow in the confidence required to drive demand and generation of relevant content. A small step forward for PwMS in accessing and using information initially could lead to larger ones in the future.

Throughout, it is important to note that meeting an individual’s need for information goes beyond just providing information: it must extend to ensuring that this information is *used*.

OUTCOMES MEASUREMENT FRAMEWORK

Introduction

An outcomes measurement framework offers a means of assessing the impact of an organisation's activities. It is the next step after a theory of change in thinking through the impact that an organisation has for its beneficiaries. The framework presented here concentrates on the outcomes presented in the theory of change. It could be used by any organisation in the MS sector in assessing the effectiveness of its information provision activities, and learning how to improve them.

Priority outcomes for information providers

In moving from a theory of change to an outcomes measurement framework, the first step is to prioritise outcomes. A priority outcome is one that matters most to the topic at hand, is particularly important to achieve, and may be within the control of an organisation. This prioritisation helps to show what needs to be measured.

NPC interviewed a range of stakeholders, including many of the attendees at the theory of change workshop, in order to establish the priority outcomes in the provision of information to people with MS.

Three outcomes emerged as clear priorities. These reflect what stakeholders felt could be achieved by provider organisations in the short term.

- **PwMS are more able to access, absorb and use information.** This is the most important outcome of the theory of change, as it refers most directly to PwMS obtaining and utilising information. Importantly, it can be broken down into three distinct stages:

Table 1: The three stages of PwMS' information access and use

Stage 1	Stage 2	Stage 3
Providers of information come to know more about the health literacy of PwMS, particularly in the initial stages of their MS, and adapt their information accordingly. This stage is particularly important if there are systematic ways in which some groups of PwMS might have lower health literacy than others. The patient activation level of an individual is also another way of segmenting and personalising information—and meeting the individual where they are at.	**Providers of information come to know more about how PwMS absorb and use information, engage PwMS in a dialogue about information usage, and adapt their information as required.**	**A longer term goal is for providers to help PwMS to increase their health literacy, allowing PwMS to absorb and use more advanced or more technical information.**

- **PwMS develop stronger skills to navigate systems (employment, health, social care, welfare).** Information is key in navigating a range of social systems, including the health care system. Navigating a complex social system involves understanding the roles and responsibilities of other agents, including what to expect from them. A solid information base is key to PwMS being able to interact with a range of systems with confidence.

- **PwMS feel able to take responsibility for gathering and assessing information.** Patient activation, which links levels of knowledge to goal-orientation and self-management, touches on how PwMS feel about gathering and assessing information. It also starts to connect information to behaviour change.

Indicators, metrics, and data collection

The following tables show how the outcomes from the theory of change can be measured. We provide indicators for each outcome, as well as standardised metrics and suggestions for collecting data. These are not necessarily all individual data collection needs. Indicators can be combined, for instance into one survey or qualitative discussion.

Table 2: Methods of measurement for three priority outcomes

Outcome	Indicator	Metric	How to collect	Comments
Priority outcome 1: PwMS are more able to absorb and use information	Providers know more about the health literacy levels of PwMS	Health Literacy Questionnaire (HLQ) is a valid and reliable measure	PwMS complete survey before and after interaction with information provision	In the short term, the goal is to understand and acknowledge the information needs of PwMS, and account for different levels of health literacy by changing information resources
	PwMS report more confidence in using information and greater use of information	None currently available	Secondary data or survey data on user consumption of information and profiling info on who is using information, and whether it is reaching target groups	Feedback on how information is being used will enable understanding of the impact it is having on lives of PwMS
	There is an increase in the health literacy of PwMS	Health Literacy Questionnaire (HLQ); the Media Health Literacy (MHL) measure found to be effective in identifying groups at increased risk of poor health literacy (adolescents)	PwMS complete survey before and after interaction with information provision	In the longer term, the goal is to raise the level of health literacy among PwMS Public Health England demarcate three levels of health literacy (functional, interactive and critical)
Priority outcome 2: PwMS develop stronger skills to navigate social systems	PwMS report feeling more able to navigate social systems More PwMS access benefits	None currently available	Interviews with PwMS Administrative data on benefits claimed	Validated psychological scales to measure ability to cope including Ways of Coping Scale (WOCS); more specific measures such as OECD International Network on Financial Education (INFE) Financial literacy survey instrument could be relevant. Macmillan evaluated impact of benefits advice information using data on which benefits were claimed and interactions with demographic data
Priority outcome 3: PwMS feel able to take responsibility for gathering and assessing information	There is an increase in the patient activation levels of PwMS	Patient Activation Measure (PAM) is a patient-completed measure with a 0–100 score, divided into four levels for practical use	PwMS complete survey before and after interaction with information provision	Stroke Association evaluation of after-stroke services in Kent used postal surveys and interviews around provision of information and signposting

Table 3: Methods of measurement for non-priority outcomes

Outcome	Indicator	Metric	How to collect	Comments
Good quality information is passively available or actively distributed as appropriate, and is accessed by users	Resources meeting required quality available in increased range of topics Resources being accessed	The Information Standard	Assess resources: a) those meeting the information standard b) whether the range is sufficient to meet the different needs of PwMS, and c) whether it is accessible/ easily found Count downloads	Given the impossibility of controlling all information, measurement of outcome can be based on provision of information at minimum standard in range of topics
PwMS feel there is trustworthy, quality information	PwMS report higher levels of trust in existing information	None currently, but measures of trust in institutions or trust in others could be adapted	Interviews with PwMS	When evaluating impact of their information resources, Macmillan found it difficult to find representative group (skewed towards older).
PwMS have greater emotional and psychological resilience	PwMS report feeling more resilient and able to cope with change	Validated psychological scales include Wagnild and Young's Resilience Scale (14- item) and Duckworth *et al.*'s The Grit scale (8- item)	PwMS complete survey before and after interaction with information provision	There are many well-being scales that could be relevant here, such as Warwick Edinburgh Mental Well-being Scale (7- or 14- item)
PwMS feel more able to develop social and other goals	Increased number of PwMS with a sense of control over their destiny and/or confidence in their ability to make decisions.	A range of possible validated psychological scales, including Duttweiler (1984) Internal Control Index (28- item) and Alternative locus of control scale (13-item) (Rotter 1966)	PwMS complete survey before and after interaction with information provision	
PwMS feel less isolated	PwMS report feeling less isolated	Social Disconnectedness Scale (8-items) (Cornwell and Waite 2009)	PwMS complete survey before and after interaction with information provision	Can be assessed 'subjectively' (through feelings of isolation as reported by PwMS themselves), or 'objectively' (by assessing whether or not PwMS has become more integrated in social networks). Lubben Social Network Scale Revised (LSNS-R) is a validated psychological scale relevant to latter
PwMS are motivated to share information	PwMS contributions to information sources	None currently	Output data. Interviews with PwMS	
Health care professionals (HCP) professionals are motivated and know about information resources	HCPs have increased knowledge about information resources and report feeling more motivated to share information	None currently	Interviews or survey questionnaire with HCPs	
PwMS direct the type of information they want to see	PwMS reported satisfaction with information PwMS submit information requests	None currently	Dependent on feedback mechanisms developed. Monitoring information on user engagement, and survey feedback	
PwMS generate and exchange information	Level of PwMS produced information/ knowledge	None currently	Outputs on information forums and other platforms	

Implementing the outcomes measurement framework

As discussed, three key outcomes in the theory of change were prioritised: PwMS accessing, absorbing and using information, PwMS feeling more able to navigate social systems, and PwMS feeling able to gather and assess information themselves. The theory of change also shows feedback loops in how MS information providers can continually improve the quality and relevance of their content based on insight into users and demand from users. As such, there is a process of development because early outcomes support later outcomes. In implementing the outcomes measurement framework, then, it is important for MS information providers to think about the chronology of outcome measurement and to build on existing practice.

In order to improve service delivery the first step is greater understanding of beneficiary need, but the final step is the evaluation of information provision activities to check whether they are having a positive impact on the lives of PwMS. The steps below summarise how information providers can apply the measurement framework, explaining how to progressively use different kinds of evidence to develop, assess and improve provision.

Step 1: Gather insight on users

Data collection should first focus on gathering insight on PwMS who use information resources, and those who don’t. Specifically, information providers should:

- obtain better profiling information to get a clearer sense of who is using resources and if that is changing
- get feedback from the spectrum of PwMS on the extent to which the information they are accessing matches their immediate needs; and
- gain insight into how information is being used, and what changes it is enabling in people’s lives (the further reaching outcomes of the theory of change).

This could entail a combination of qualitative engagement, analysis of profiling information and user journey mapping.

Step 2: Take a proportionate approach to information collection

Next, existing metrics on outcome indicators (see above) can be drawn together into a questionnaire, with questions added for indicators where no metrics currently exist. Information providers should take a proportionate approach to information collection. In other words, some interactions in providing information to PwMS will be very light-touch so it is important not to overburden users with form filling, which could damage their experience. Information providers also need to be realistic about what will change as a result of information provision; a small, one-time interaction is unlikely to have far-reaching effects.

Step 3: Build on existing data collection options

In implementing the outcomes measurement framework, it is crucial that existing information is used in conjunction with any additional information that is collected. For instance, some information might be taken during helpline calls or online store purchases, and this information should be linked to support continuous analysis of user characteristics.

Step 4: Administer a universal, short automated survey

The key questions for this survey are whether the user can absorb and use the information, and whether it helps them. With reference to priority outcome 1 (PwMS are more able to absorb and use information) the first step would be asking PwMS whether they feel able to absorb and use information, and whether they feel any information they have received has been useful. Data could be gathered through a very short automated survey, ideally linked to any profiling information that has been gathered.

Step 5: Gather qualitative data from a small sample covering the breadth of user characteristics

Qualitative data helps an information provider's understanding of its users, and can be used to explore how information is being used. Qualitative feedback is best gathered from a small stratified sample of users, using either online self-completion or telephone follow-ups. Qualitative data could help information providers to measure whether priority outcome 2 (PwMS develop stronger skills to navigate social systems) has been achieved.

Step 6: Make continuous use of a user panel

A user panel is an excellent resource for testing web resources and new information content. Information providers should ensure that the user base includes the full range of types of individual they hope to reach. This range should closely match any user segmentation drawn from profiling information. It would also enable information providers to check whether priority outcome 3 in the table above (PwMS feel able to take responsibility for gathering and assessing information) is being achieved, as questions could be asked directly on how able PwMS feel to gather and assess information themselves. The user panel can also be adapted for use in the co-design and testing of material.

Step 7: Utilise sampled mixed methods research at a later date

Further-reaching outcomes such as changes to health literacy and feeling more able to navigate social systems require a more detailed understanding of users, and are not suited to universal data collection. It is not clear how long it takes users to increase their health literacy and to start to realise changes in their lives. These questions should form part of a focused study rather than part of continuous monitoring. We would recommend sampling users and conducting follow-up phone calls, with a combination of open and closed questions. We would then recommend a 'before and after' approach for the three prioritised outcomes: comparing 'before' and 'after' scores is a useful way to measure change. Since interaction with information is usually more of an ongoing interaction than a one-off 'treatment', special care must be taken to identify appropriate 'before' and 'after' time points.

TOWARDS A USER JOURNEY

A user journey is a mechanism organisations can use to trace the progress of an individual towards their end goal. Specifically, user journeys chart the various interactions between an individual and an organisation, reflecting on the outcomes achieved along the way. User journeys are an extremely useful tool for mapping interaction with services and are frequently used in website design to explore the routes that users take through online products and services.

User journeys and information strategy

User journey thinking is closely linked to an organisation's information strategy. A key part of an organisation's information strategy might be that information should be not only *obtained* by PwMS but also *used* by them, and increasingly *driven* by them too. Information is central to supporting decision-making and enabling behaviour change. The theory of change illustrates how this can be achieved through a process of intermediate changes, while the outcomes measurement framework details how this process can be measured and monitored.

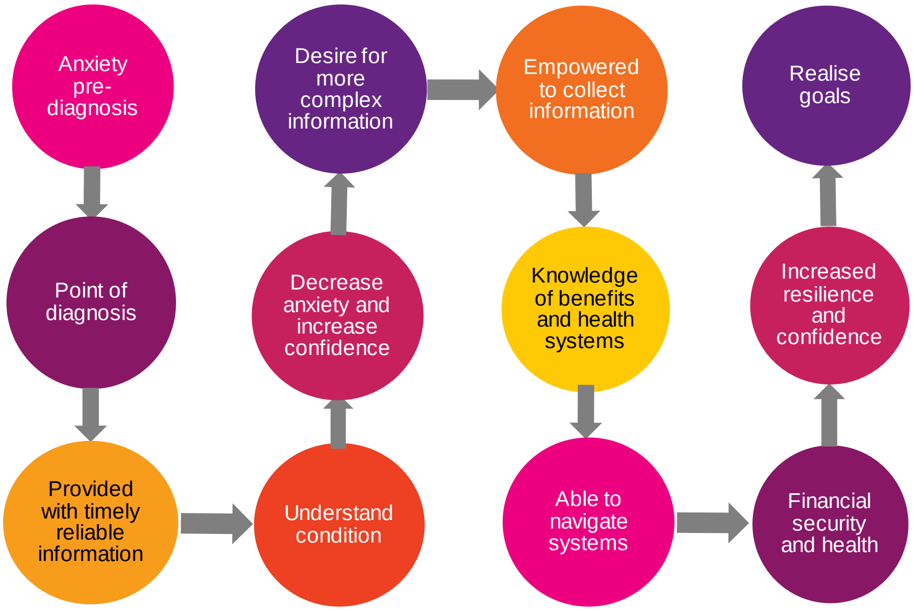
Sketching out user journeys helps illustrate the context in which the outcomes measurement framework can be enacted and provides the starting point for market segmentation. For instance, we can distinguish between situations in which the user needs factual content and other situations in which the user's needs are linked to empowered decision making or contexts where the evidence base is contested. The user journey also starts pre-diagnosis, which might link to strategic interests in providing information to people who may have MS before the point of diagnosis.

Depicting user journeys within the information ToC is a useful corrective for service delivery organisations that take a provider-driven orientation. The information ToC in this report necessarily starts with service providers' needs and activities in producing information. However, the outcomes revolve around an individual with MS who is enabled to seek, use and contribute to information in a personalised way. This evolves through a series of feedback loops, and may represent a second or third phase in the implementation of an information strategy. See the example user journey through information usage, shown below.

An example user journey through diagnosis

As the theory of change makes clear, PwMS are at the centre of information provision activities. It is particularly important to keep the notion of *empowerment* as central to the idea of what information provides. The ideal MS user journey ends with a feeling of self-confidence and positive behaviour change. Of course, individuals will have different journeys, but goals may be similar.

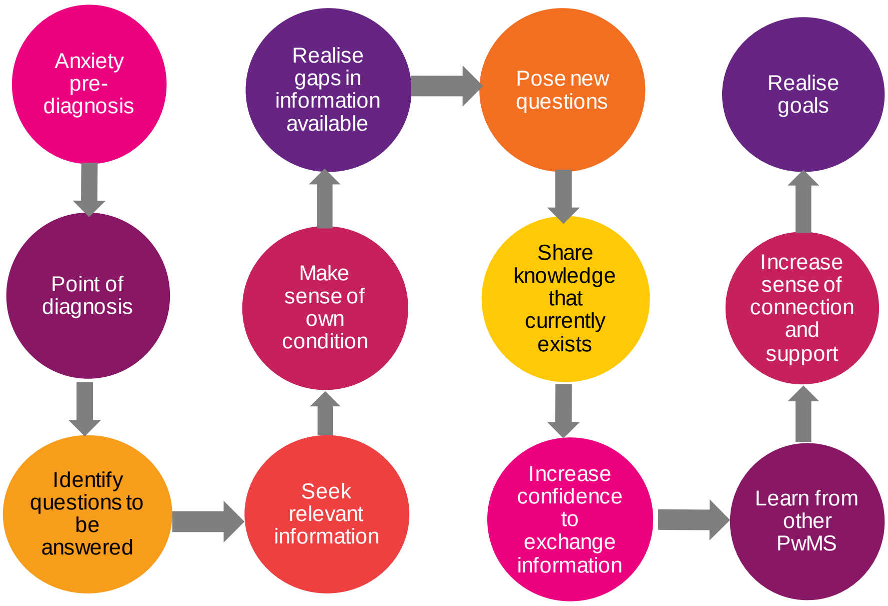
Figure 2: A user journey for a person with MS interacting with information to manage their condition



An example user journey through information usage

The goals of the ToC relate to PwMS' use of information, and how their participation in an information network can support their autonomy. This includes the role PwMS play in seeking, using and sharing information. This may entail gradual steps, as shown below.

Figure 3: A user journey for a person with MS participating in an information network to build content relevant to them



Tips for producing a user journey

We can note that the user journey begins slightly earlier than the theory of change, since a PwMS may experience anxiety before their diagnosis. How to provide information pre-diagnosis is an important strategic consideration for MS information providers.

When designing a user journey, the following key questions might be useful:

- What is the starting point of the user's journey?
- What are the most important points between the start and goal of the journey?
- Where do services provided by different organisations fit into this journey?
- What are the outcomes achieved by those services?

With reference to information provision for MS, mapping user journeys would allow information providers to clarify what they want to achieve in each interaction with a PwMS in the movement towards empowerment. When mapping user journeys:

- **Be explicit about who you are mapping the journey for.** In other words, it is important to be clear who the beneficiary is, and what their needs are.
- **Think about the scale of your user journey**. User journeys can be articulated at many different levels or scales—for instance, helping PwMS to navigate the benefits system can be a user journey in and of itself, or it can feature as part of a wider journey (towards autonomy). It is also important to think about the timescales involved as well.
- **Think about the goal of your user journey.** That is, be clear about where you want your user to end up, and what is a realistic endpoint.

SHARED MEASUREMENT

Shared measurement—when charities working on similar issues and towards similar goals reach a common understanding of what to measure in terms of the outcomes and impact of their work—has many potential advantages for the MS sector. NPC has found that shared measurement brings economies of scale, collaboration and improved impact practice, while the resulting shared data improves services and drives strategy, increases engagement with commissioners and supports funding applications.[17] It allows organisations to speak with a louder voice, both individually and collectively.

This report could serve as a foundation towards a future shared measurement approach. A journey to shared measurement around information provision for the MS information provision sector could take several forms, but one option is depicted below.

1. The first stage is for a number of different information providers make a commitment to impact measurement, and to continual improvement. Measuring impact, and using it to improve services, requires expertise and capacity, but a recognition of its importance in service delivery is an important starting point.
2. The second stage is for participating organisations to adopt shared outcomes. An intermediate stage before this might be that these different organisations adopt *similar*, but not exactly the same, outcomes. This would act as a benchmark of the success of their different activities.
3. If shared outcomes are used, then the implementation section of the outcomes measurement framework traces out how the sector can reach the third stage: the use of the same metrics to measure the same outcomes in the same way.
4. The final stage of shared measurement is when the sector works together to deliver the best outcomes for beneficiaries. At this point, different organisations within the sector can be confident that their activities interlock with those of other providers. Each specific organisation can then focus on its specialist outcomes with confidence that they contribute in a strategic way to improving the lives of PwMS.

Underlying the sector journey to shared measurement is the principle of collaboration between organisations, sharing knowledge and expertise wherever possible.

CONCLUSION

In this report we have introduced a set of common outcomes around the provision of information to PwMS. The theory of change sets a shared agenda and ambition: that PwMS have the knowledge, skills, and confidence to live with their MS and to identify and achieve their goals.

This is a great foundation from which to build a coherent, effective and tailored set of services, but is just a first step. Research in the MS sector on the outcomes of information provision is at an early stage, and needs both time and funding to produce robust evidence. It will be important for organisations to build a stronger picture of users' needs and preferences, which entails continuous engagement and service user feedback to refine and improve provision.

The provision of information to people with MS exists in the wider context of changes to the way we understand good health and the increasing power of digital information technologies. An ongoing interaction between user and provider is also crucial to effective engagement on digital platforms, which offer real potential as a source of support and communication. In this report we do not focus on the specific media through which information could be communicated or monitored. Instead we aim to establish some more general strategic principles for the MS sector in its information provision. These principles, we hope, can guide the sector on how to take up and use new technologies to best effect.

A second wider context is the different potential roles of health charities as the role of the state in the healthcare system changes. NPC's 2014 discussion paper *Supporting good health* identifies seven roles for health charities. Any MS information provider should plan for changes in the statutory system and the consequences these will have on their activities.

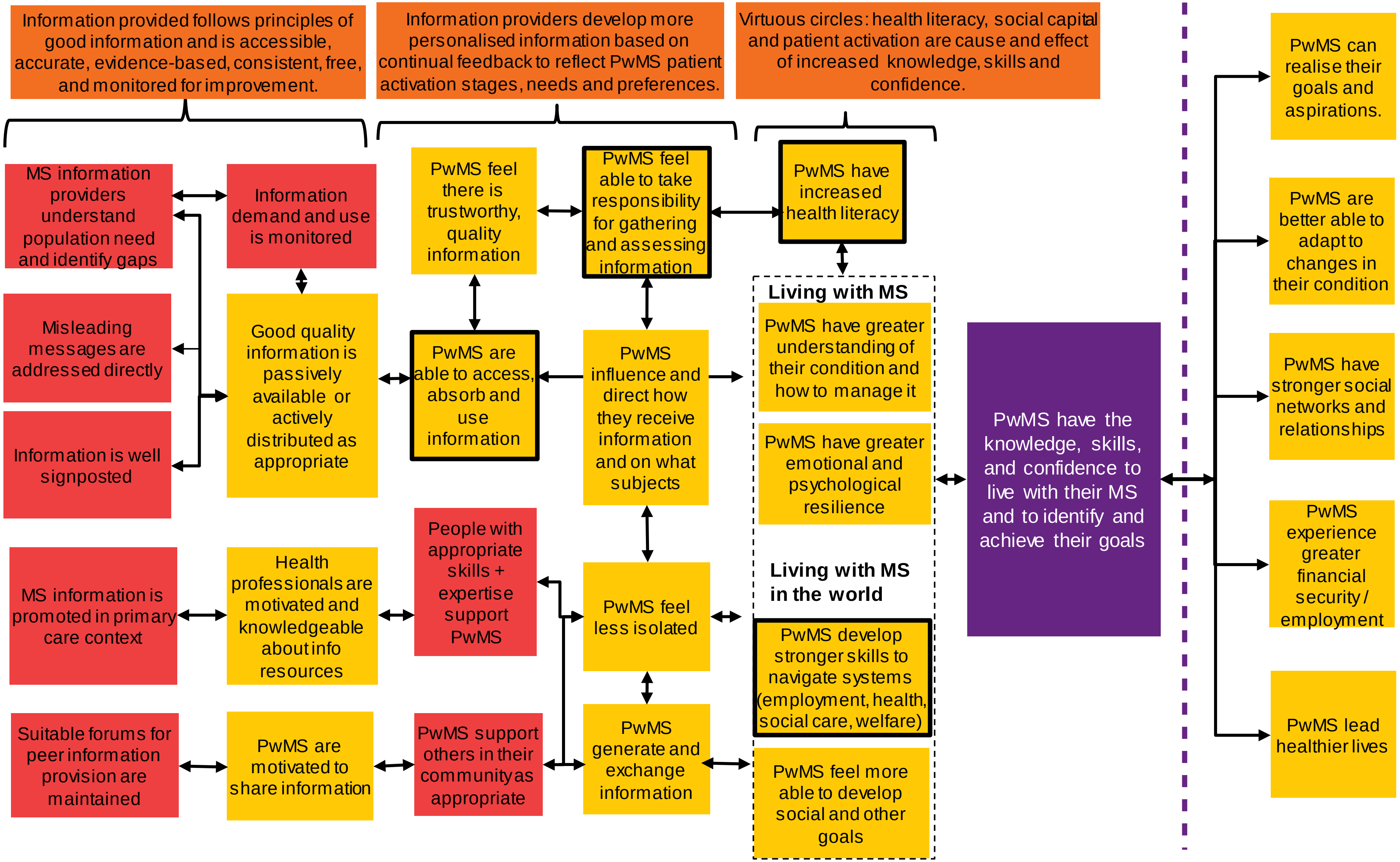
Research in the MS sector on the outcomes of information provision is at an early stage, and needs both time and funding to produce robust evidence. However, insights from other sectors may offer useful ideas. In behavioural psychology and economics, for instance, there is a lot of thinking around how incentives, 'defaults', and the way a message is delivered can all change behaviour. This can also link to how technical changes (often as small as adding a checkbox to an electronic form before it can be submitted) in information collection can have a big impact.

Finally, the role of sector leadership is likely to remain central. At the same time, the MS sector may in the longer term need to think about how it engages work health care professionals outside the sector to support them to diagnose MS. If patients sometimes suffer due to a low understanding of the complications associated with MS, then important issues of sector boundaries and collaboration are raised.

We hope the information contained in this document proves instructive to the MS sector, enabling more collaborative and joined-up information provision, and better outcomes for beneficiaries.

APPENDIX

Theory of change for providing information for people with multiple sclerosis



Information provided follows principles of good information and is accessible, accurate, evidence-based, consistent, free, and monitored for improvement.

Information providers develop more personalised information based on continual feedback to reflect PwMS patient activation stages, needs and preferences.

Virtuous circles: health literacy, social capital and patient activation are cause and effect of increased knowledge, skills and confidence.

MS information providers understand population need and identify gaps

Information demand and use is monitored

Misleading messages are addressed directly

Information is well signposted

Good quality information is passively available or actively distributed as appropriate

PwMS feel there is trustworthy, quality information

PwMS are able to access, absorb and use information

PwMS feel able to take responsibility for gathering and assessing information

PwMS influence and direct how they receive information and on what subjects

PwMS have increased health literacy

MS information is promoted in primary care context

Health professionals are motivated and knowledgeable about info resources

People with appropriate skills + expertise support PwMS

PwMS feel less isolated

Suitable forums for peer information provision are maintained

PwMS are motivated to share information

PwMS support others in their community as appropriate

PwMS generate and exchange information

Living with MS

PwMS have greater understanding of their condition and how to manage it

PwMS have greater emotional and psychological resilience

Living with MS in the world

PwMS develop stronger skills to navigate systems (employment, health, social care, welfare)

PwMS feel more able to develop social and other goals

PwMS have the knowledge, skills, and confidence to live with their MS and to identify and achieve their goals

PwMS can realise their goals and aspirations.

PwMS are better able to adapt to changes in their condition

PwMS have stronger social networks and relationships

PwMS experience greater financial security / employment

PwMS lead healthier lives

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REFERENCES

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[1] NHS England (2014) *Five year forward view*.

[2] Burke, J. (2013) *What is MS?* MS Society.

[3] Burke, J. (2013) *What is MS?* MS Society.

[4] Windle, K. *et al*. (2010) *Measuring the outcomes of information and advice services: Final report*. Personal Social Services Research Unit.

[5] Stewart, A. and MacIntyre, G. (2013) *Advocacy: Models and effectiveness.* Institute for Research and Innovation in Social Science, University of Strathclyde.

[6] Köpke, S. *et al*. (2014) 'Information provision for people with multiple sclerosis', *Cochrane Database Systematic Review 4*.

[7] Methley, A. *et al.* (2014) 'Experiences of UK health-care services for people with multiple sclerosis: a systematic narrative review', *Health Expect* 18(6): pp. 1844-1855.

[8] Coulter, A. and Ellins, J. (2007) 'Effectiveness of strategies for informing, educating, and involving patients', *British Medical Journal* 335: pp. 24-27.

[9] Wollin, J. *et al.* (2000) 'What people with newly-diagnosed MS (and their friends and families and friends) need to know', *International Journal of MS Care* 2(3): pp. 29-39.

[10] Heesen, C. *et al.* (2004) 'Decisional role preferences, risk knowledge and information interests in patients with multiple sclerosis', *Multiple Sclerosis* 10(6): pp. 643-650.

[11] Heesen, C. *et al.* (2007) 'Informed shared decision making in multiple sclerosis—inevitable or impossible?', *Journal of Neurological Science* 259(1-2), pp. 109-117.

[12] Puttick, R. and Ludlow, J. (2013) *Standards of evidence: An approach that balances the need for evidence with innovation*. NESTA.

[13] Public Health England (2015) *Local action on health inequalities: Improving health literacy to reduce health inequalities*, p. 5.

[14] MS Society (2013) *A lottery of treatment and care: MS services across the UK*. MS Society.

[15] Hibbard J., Mahoney E., Stockard J., and Tusler, M. (2005) 'Development and testing of a short form of the Patient Activation Measure'. *Health Services Research*, 40(6): pp. 1918–30.

[16] Hibbard, J. and Gilburt, H. (2014) *Supporting people to manage their health: An introduction to patient activation*. The King's Fund.

[17] Handley, S., Sabri, F. and Kazimirski, A. (2016), *Shared measurement: Greater than the sum of its parts*. NPC.

TRANSFORMING THE CHARITY SECTOR

NPC is a charity think tank and consultancy which occupies a unique position at the nexus between charities and funders, helping them achieve the greatest impact. We are driven by the values and mission of the charity sector, to which we bring the rigour, clarity and analysis needed to better achieve the outcomes we all seek. We also share the motivations and passion of funders, to which we bring our expertise, experience and track record of success.

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