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Measuring supported self-management

Five steps to help teams choose approaches

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Contents

1. What is supported self-management?

Supported self-management is part of the NHS Long Term Plan's commitment to make personalised care the norm. We use the term to mean the ways that health and care services encourage and support people to manage their ongoing physical and mental health conditions themselves. It centres around a person and their family so is nuanced to meet individual needs and can take many forms, including:

- sharing experiences with other people with the same condition (peer support)
- information, education and training opportunities
- health coaching
- digital and remote technologies to monitor a condition or symptoms and to share information
- practical activities such as exercise classes.

You can learn more about the different types of supported self-management here.

Why measure?

Measuring involves establishing what something is or achieves, such as its properties, qualities, values or effects. It is about tracking progress or providing information to inform decisions, not collecting information for the sake of reporting.

For supported self-management:

1. Measurement can be **part of an intervention** to support self-management for an individual or population group, eg:
    - to identify whether and to what degree people are self-managing
    - to identify health inequalities in self-management behaviours or support
    - to assess the self-management support needs, knowledge and confidence of people with long-term conditions and their carers
    - to facilitate shared agenda setting and person-led goal setting

- to help tailor interventions to suit an individual’s or population’s needs.

2. Measurement can help **evaluate interventions** to support self-management, eg:
   - to identify whether self-management activities are improving outcomes
   - to explore the extent to which professionals or services are supporting self-management
   - to benchmark and check whether services or systems are achieving their goals and national and local priorities
   - to inform how services could be improved
   - to test different approaches to see which have the greatest impact and should be prioritised/expanded, and which should perhaps be decommissioned.

Measuring is not about collecting information for the sake of reporting. It is about tracking progress or using information to inform decisions. It may help you determine how best to help an individual through tailoring support based on their needs and goals, or identify how self-management initiatives or services can be improved to meet more people’s needs.

About this guide

This guide describes five steps for health and social care teams to follow when planning how to use measurement based on evidence and good practice.

The steps will help you decide how to collect information that is right for you and the populations you serve, and you could use this guide when co-producing measurement approaches with people with long-term conditions and their families and carers. We give examples throughout to show how teams have used measurement in supported self-management.

We share latest resources for supported self-management and personalised care on our online platform. To join, contact england.supportedselfmanagement@nhs.net

Box 1: Measuring as part of supported self-management to tailor support to individuals

As part of an intervention to improve the wellbeing of young carers, a social care team in the North East used a tool to identify their individual needs.

In a one-to-one conversation with a social worker, the young person was asked to use a star diagram to 'map out' how they were feeling about different aspects of their lives, where they felt they were coping well and where they might value support. Using this visual tool kept things simple, was less threatening and helped the young person see patterns.

Once a young carer had identified their strengths and challenges, the social care team worked with them to plan person-led goals and co-produce next steps. The team signposted the carer to short courses, websites, peer support groups and activities tailored to the young person's priorities.

After 12 weeks, each young carer completed the tool again, to see whether their needs were being met and what other support might help.

Box 2: Measuring the impact of supported self-management

Health and social care teams in London used an interactive workbook to learn how to better support people who had had a stoke with self-management.

The health and care system wanted to know whether this workbook was useful or if it should invest in other types of training instead, and so measured its impact on professionals and the people they supported.

- **Professionals:** Health and social care teams working in the community and in hospital completed surveys about their knowledge, attitudes and behaviours before and after using the workbook. The workbook improved their approach and behaviours towards self-management.
- **People who had had a stroke:** The system compared confidence in ability to self-manage (self-efficacy) between people supported by professionals given the workbook and people supported by professionals who had not seen the workbook. The former were more confident to self-manage and had a better quality of life. These benefits lasted for at least three months after people had contact with healthcare teams.

Measuring provided evidence that the workbook was having the desired effect, and the system decided that it was cost-effective to keep investing in this approach. Other areas also started using this resource.

2. Steps to measuring supported self-management

Measurement as part of supported self-management can take many forms. There is no single ‘best’ approach; the right approach for you will depend on what you want to achieve and the time and resources you have available. A multifaceted approach may work best.

These five steps can help you choose the best approach for you:

Step 1: Identify and involve stakeholders

Step 2: Clarify what you want to achieve

Step 3: Decide what to measure

Step 4: Decide how to measure

Step 5: Plan who, when and where to measure

The steps are interlinked but do not need to be taken sequentially. They are the same whether you are choosing measures to:

- assess needs and tailor interventions for an individual or population
- evaluate whether a supported self-management initiative is making a difference.

Step 1: Identify and involve stakeholders

Think about who will be affected by your decisions about measuring supported self-management and try to involve those stakeholders. Co-production is an essential part of supported self-management.

Involving stakeholders in your planning means:

- everyone has a shared vision about what you want to achieve
- you collect information that people want and can use
- you get new ideas about what to measure and how to do so

- you have the help or resources you need
- you can use consistent approaches across your wider system and services, tracking changes over time and embedding measuring supported self-management across the system.

You may want to involve people:

- who commission, pay for or make decisions about services
- with long-term conditions
- who are carers for people with long-term conditions
- who provide supported self-management interventions or services
- who will collect and analyse information
- who are experienced in choosing or using measures.

Sometimes people make decisions about what to measure without consulting others. This can mean different services or teams use varying measures. The benefit of using the same measures as others in your health and care system is that you can then track changes over time and embed measuring supported self-management across the system.

You could use a stakeholder map to identify who to engage. For example, to complete the simple map in Figure 1, insert names or roles according to how interested and how influential the stakeholder will be. Then seek the involvement of those in the top right-hand box, eg by holding co-production meetings or conducting short interviews with them.

Figure 1: Example stakeholder map template

Step 2: Clarify what you want to achieve

Stakeholders can have different priorities or reasons for wanting to measure. Knowing what these are can help you decide together whether or not to try to meet everyone's needs, and if you need to expand your approach.

Don't jump straight into trying to choose a measure, survey or tool without being clear about what you are trying to achieve. If you first think through what you are doing and why, you will find it easier to decide what to measure and how.

Box 3: Elements of supported self-management you could measure

Elements related to populations:

- **identifying** population groups most at risk (Box 4 gives an example)
- examining the needs of **populations** or communities to help plan appropriate initiatives and address health inequalities.

Elements related to people you are supporting:

- helping people identify and achieve **goals** that are important to them
- identifying whether and **how** an individual is self-managing
- identifying people's **needs** and tailoring support to match
- understanding whether people and their carers have the **knowledge**, skills, confidence and motivation to self-manage well.

Elements related to professionals and systems:

- understanding the extent to which a professional, team or system is **supporting** self-management
- judging the impact or value of **initiatives to help professionals** or systems better support self-management.

Elements related to supported self-management approaches:

- checking whether people have a good **experience** of supported self-management initiatives
- understanding elements of supported self-management that you could **improve** or develop further
- judging the **impact** or value of supported self-management for individuals, populations or systems

- **comparing** different types of supported self-management to decide which is the most effective or best value for money.

Box 4: Measuring to understand population health needs

To help address health inequalities, allied health professionals in the Midlands wanted to understand the health needs of ethnic minority groups and potential barriers to self-management.

First, they reviewed clinical records and evidence to examine the health outcomes for different population groups. They found that people from some South Asian communities had a higher risk of heart attack and stroke, and poorer outcomes afterwards, and that these communities were less active. They interviewed and surveyed people from local communities to explore whether increasing physical activity might be a priority, attitudes to physical activity, how often they exercised and any barriers to being more active.

South Asian girls and young women aged between 12 and 18 years were less active than others, influenced by personal, social, cultural and environmental factors. The team decided to target this group for support.

They used an existing survey about physical activity, but as it had not been validated in diverse populations, they also interviewed young people, parents, teachers and community groups to add relevant information.

The team then worked with a reference group of community members to review and interpret all the information. Seeing tangible data acted as a catalyst to taking action and this group started programmes to encourage more physical activity among girls and developed guidance for schools.

Mapping what you want to achieve

You can use an outcomes map, sometimes called a theory of change or logic model, to visualise the difference you want to make. Figure 2 shows an example; you need to insert your activities and the impacts you hope these will have immediately and in the longer term. You do not need to measure everything in your outcomes map. Being clear about the pathway will focus you on measuring what matters to you and your stakeholders. Figure 3 gives an example of how a team in the East of England ran online self-management education groups with people with diabetes, to encourage them to eat healthily and be more active, and ultimately stay healthy for as long as possible.

Figure 2: Outcomes map showing activities and desired impacts

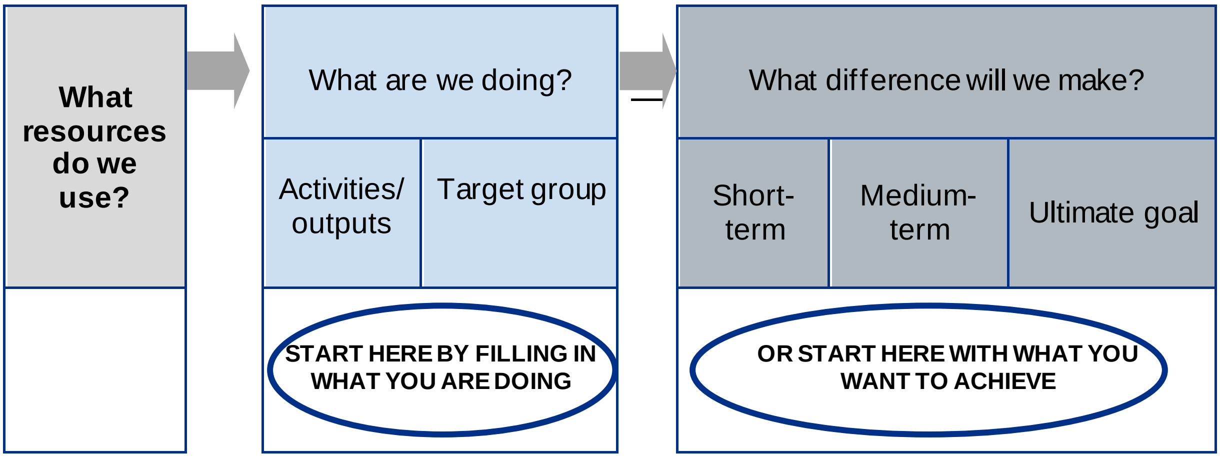

Figure 3: Outcomes map for online diabetes education

What resources do we use? (inputs)	What are we doing?		What difference will we make?		
	Activities/ outputs	Target group	Short-term	Medium-term	Ultimate goal
• Patient educators • Clinical supporters • Online platform • Information materials • Posters and leaflets at general practices • Training sessions for educators • Total cost £10,000	Five courses run per year Each course consists of weekly 2-hour sessions for 6 weeks	Adults with Type 2 diabetes 10 in each course (total 50 people per year)	Participants: • have more **knowledge** about self-managing their diabetes • are more **confident** to manage their diabetes	Participants: • change their **behaviour**, such as improving their diet or exercise • have better **blood sugar** control	Participants: • **live longer** • stay as **healthy** as possible

In the example in Figure 3, imagine you are part of this team. Your goal is to help people with diabetes live longer and stay as healthy as possible. This will not be measurable in the short term after running an online course. Instead, you could measure a more immediate impact such as whether the course improves people's confidence to manage their diabetes. You are still focusing on your goal but measuring ‘improved confidence’ as an indicator of progress, rather than the endpoint.

Check the short and medium-term impacts you noted in your outcomes map really reflect the difference you want to make. People often mistake ‘outputs’ for ‘outcomes’.

- **Outputs** are **things** you create or do, such as produce an information booklet or online training course or run health coaching sessions.
- **Outcomes** or impacts are the **differences** you make, such as more people exercising regularly, people finding it easier to manage their blood sugar or fewer people being admitted to hospital. The NHS Outcomes Framework prioritises mortality, morbidity and people’s experience of using services.

Using an outcomes map can:

- clarify the difference you want to make for people using services, staff or systems, which helps when prioritising what to measure
- show your plans in a visual way, which can be useful when engaging with stakeholders
- help you consider your assumptions or the steps to achieve your goals. For example, rather than assuming people can access and use the online course you have created, test this by measuring the number of people viewing the course, their demographics and where they heard about it. If few can access the course, you cannot reliably measure its impact.

Box 5 provides an example of how an outcomes map can be used to test the validity of assumptions.

Box 5: Using an outcomes map to test assumptions

A community trust and a hospital trust in the South East developed self-management educational materials for people with diabetes, but people did not seem to be acting on the suggestions.

By mapping what they were doing using an outcomes map, the teams identified the key assumption that people would read and react positively to the educational materials.

They tested this assumption using interviews, focus groups and surveys to find out what was important to people with diabetes and how they reacted to information. They found that people most at risk resisted messages about self-management.

The teams then tested different ways to frame messages and the best wording to use. They found that people were more likely to accept and be persuaded by health promotion messages when they felt they had control and choice, and to resist messages that implied they were doing something ‘wrong’, such as ‘failing’ to eat healthily or exercise.

The teams rephrased their educational materials and on surveying people with diabetes found they were more receptive to the new messages and were starting to change what they ate.

An outcomes map can also be helpful if you want to choose a tool to help you work one-to-one with someone. It can help you think about whether you want a tool to:

- identify the person’s support needs
- understand their knowledge
- learn about their current self-management behaviours
- identify barriers to self-management
- see how confident they are about self-managing.

It can also help you map what type of support might be available to people, and whether or not you plan to use the tool to track changes over time.

Step 3: Decide what to measure

You need to be explicit about **what** you will measure, because this will influence the methods you use to collect the information. For instance, for the earlier example about an online diabetes education course, you may want to measure whether taking the course makes people feel more confident about managing their diabetes. You can be more precise by defining what you mean by ‘more’ and ‘confident’. Setting a target can help you do this, eg:

- At the end of the course, 66% of people will say they feel more able to self-manage their diabetes than they did at the start of the course.
- After the course, 80% of people will rate their confidence 9 out of 10.
- On average, people’s level of confidence to self-manage will have increased by 10% compared to what they said at the start of the course.

You could also look at whether changes designed to improve one thing cause new issues or have potential negative impacts elsewhere – so-called 'balancing measures'. For example, with more people taking part in the online course, does the number attending in-person courses decrease?

People sometimes try to measure too many things. It can be more useful to measure fewer things well. The most important question at this stage is whether what you have chosen to measure will tell you whether your intervention is effective in meeting your goals or whether you need to refine what you are measuring.

Consider what metrics/indicators will give you useful information on what you want to measure. Robust metrics are often:

- **comparative**: so you can compare over time or between user groups or services
- **understandable:** if your team does not understand what a metric is measuring, it will be harder to use n practice as it will not feel meaningful or helpful
- **easy to quantify:** numerical information is easier to compare and monitor over time. It tells you by 'how much'. Ratios, rates or proportions are usually easier to compare than absolute raw numbers. However, qualitative information helps you answer 'why' so can also have an important place in your measurement strategy
- **able to influence decisions or behaviours**: you should be able to answer the question 'what will I do differently based on the measure?' If you cannot, the metric may not be useful.

These principles hold whether you are using measures to assess and tailor support to an individual, or the impacts of a service or intervention. Appendix 1 provides examples of what you could measure.

Step 4: Decide how to measure

Measuring does not have to be time-consuming and does not require special skills. You can measure in small and simple ways. For example, when personalising support, ask the person to rate how confident they feel managing their condition on a scale from 1 to 10, or spend a few minutes shading in a diagram to highlight what is most important to them. Such simple measures can also help track changes over time for individuals or groups. Alternatively, you can invest time and resources in more comprehensive measurement, depending on how you plan to use the information. The main thing is to choose methods that you will be able to use consistently so you can compare over time and between services if needed (see Appendix 2).

Some of the most common ways to collect information about supported self-management are:

- **surveys**, paper or digital
- **interviews**, in person, by telephone or video call
- **focus groups**, in person or virtually
- reviewing **informal feedback** such as letters, compliments and complaints and social media or website posts
- extracting information from **clinical records** or biometric data
- reviewing **service use statistics**, such as hospital episode statistics or general practice databases
- **observing**, such as watching consultations or training sessions
- reviewing processes or **documents**.

How you measure relates to **what** you want to measure. Table 1 summarises what you should think about when choosing a measurement method. You could consider using more than one method to gain a better picture.

Table 1: Questions to ask yourself when choosing a measurement method

Things to consider	Potential methods
What are you trying to achieve?	
What type of information do you need to make decisions or achieve your goals?	If you want to know how many or how often things happen, use methods such as surveys, clinical records and service use statistics. If you want to know why something happens or how people feel, interviews and focus groups can work better. It may work well to use more than one method.
What type of decisions will your measurement inform?	If you want information to make quick and relatively small decisions, such as how to support an individual, it may work well to use informal methods such as a short scale, interview or observation.

Things to consider	Potential methods
	If you want to use your measurement to decide whether to commission or decommission services or make large changes, you may need to measure larger numbers and use more robust methods, and track these over time.
Do you need to be able to generalise widely? Will the information be credible to decision-makers?	If you need to generalise, you probably need to use a method that can collect feedback from a large number of people, eg survey or clinical records. If you are trying to measure to support an individual, you probably do not need to be able to generalise, unless you are comparing with others.
Do you want to be able to track changes over time?	If you need to show trends over time, use a method where the same questions can be asked in a similar way, such as survey, clinical records or online analytics.
What resources do you have?	
What information do you already have access to?	The more information you need to collect, the more time and resources you will need. You may be able to measure using information that has already been collected, such as in clinical records or service use statistics.
Do you have the skills to implement the methods and measures or is training required?	Simple surveys and informal focus groups are relatively quick and easy to do. You may benefit from extra help to conduct interviews that are detailed or ask sensitive questions. When using validated surveys, either to assess individual needs or to evaluate initiatives, it is a good idea to allow time to train staff in how to use the tools.
How quickly do you need the information? How much time can you devote to collecting and analysing data?	If you are using tools during a patient visit, they need to be quick and easy for people to complete. Interviews and observation can take a while to organise and analyse. Surveys and reviews of clinical records and service use tend to be quicker. However, you also need to build in time for any ethical, clinical governance or data protection reviews.
Are there any financial costs? Are there any opportunity costs?	Surveys and reviews of existing records do not usually cost much compared to other methods, although you need to pay a licence fee to use some surveys. Interviews can elicit more detailed information but can be time-consuming and therefore costly.
What practical things do you need to consider?	
Will the method(s) be acceptable and accessible to your target audience?	If you want feedback from people who are not confident readers or whose first language is not English, a focus group or interview may be better than a survey, even a translated survey. You may need to adapt your approach for children, people with a learning disability and others with special needs. Everybody does not have access to the internet.

Things to consider	Potential methods
Will it be quick and easy to use the information?	You need to consider whether tools to tailor support for individuals can be loaded onto IT systems for use across teams. Interviews can generate a lot of detailed information and this will take time to analyse. Surveys can be done using online apps that generate graphs and statistics for you.

Using survey tools

Surveys are a common way of measuring supported self-management. Some systems and services develop their own surveys; others use or adapt validated surveys or scales designed and tested by others (see Box 6); you need to take care adapting existing tools because any scales will have been validated as reliable. It probably makes sense to see whether an existing tool could meet your needs rather than trying to invent something new.

Box 6: Adapting measures of supported self-management

Occupational therapists in the North West ran self-management education sessions for people with rheumatoid arthritis. They used validated scales (translated into common languages) to test whether these sessions made a difference to people's daily activities, functioning and quality of life.

Those from abroad were adapted to be user friendly and culturally appropriate for the UK, and scales were also changed to reflect what people with arthritis considered most important, working with a university to test this did not affect reliability and validity.

They then used this tool consistently in all their education programmes and showed that an educational-behavioural approach reduced pain in people with rheumatoid arthritis and improved their ability to move and function. However, it did not give enough detail about what people liked about the programme, so the therapists followed up with interviews and focus groups and used this feedback to help strengthen the programme.

Appendix 2 lists some tools for use with people with any condition (generic tools) and for use with people with a specific condition (disease-specific tools), with links to more information about them.

As with all decisions about measuring, the most appropriate tool depends on what you want to achieve and what resources you have. You need to be clear about **what** you want to measure before choosing a tool. Box 7 lists questions you could ask yourself when weighing up different tools.

Box 7: Questions to ask yourself when considering different tools

- Are you confident that the tool will measure what you are interested in? For example, do other services or systems use it? Is there an evidence base for it?
- Is it important that the tool is widely used so that you can compare your results with others?
- Is the tool practical to use? Can it be used online and in paper form? Can it be integrated into existing digital systems and viewed by multidisciplinary or integrated teams across organisations?
- Is it easy for the people you are supporting to use? Is the language user-friendly? What is the reading age? Is it available in various languages? Are there versions for children? Is it available in a form that people with a learning disability can use?
- How long does it take to complete?
- How long will it take to process and analyse?
- If a licence is needed, how much does this cost?

Step 5: Plan who, when and where to measure

The final step is finalising practical issues. You will have considered some of these points when deciding what and how to measure. Box 8 lists the types of questions you could ask yourself to finalise your plans.

Box 8: Questions to ask yourself when putting your plans into action

- **Who do you want to collect information from?** For example:
  - Do you want data about one person, everyone in a population or a group? How many people do you need data from to make decisions?
  - Are you interested in everyone who enrolled in an initiative like a self-management education course or only those who completed it?

  - Is there a group that you can compare your results to? It can be insightful to compare with people who have not taken part in an initiative or to compare the progress of an individual over time.
  - Do you need to identify individuals or can feedback be anonymous?

- **Who will collect information?** For example:
  - Does the information need to be collected by a clinician or can others such as reception teams and support workers help?
  - Is it appropriate for the team running an initiative to collect information or could this influence whether people give honest feedback?
  - If an invitation is sent by email or text, will people know and respect the sender enough to provide feedback?
  - Have you allocated time and resources to train staff to use the tool?

- **When will you collect information?** For example:
  - Before and immediately after an intervention.
  - How long after providing support will you collect data? You may be able to see changes in attitudes immediately, but changes in clinical indicators like blood pressure may take longer.
  - Do you want to repeat measurements over time to see how long any impacts last? Your initiative may improve people's attitudes for a few weeks, but not in the longer term.

- **Where will you collect information?** For example:
  - Will you collect information when people attend the service or can they do this at home?
  - Will they need access to a computer, kiosk or wearable device?

- **How and when will you analyse and use information?** For example:
  - Will information collected about individuals be available across IT systems so multidisciplinary teams can see and use it when providing support? Are there any implications for IT interoperability across records systems?
  - Will you create a summary report each month, quarter or year and discuss this at a team meeting or board meeting?
  - Will you use visual dashboards or written reports? What format will be most useful and impactful for decision-makers?
  - How will you share what you learn across your system?

Planning when to measure

This will depend on what you want to find out:

- **Measure before an initiative** if you are interested in people's preferences, needs or goals.
- **Measure during an initiative** if you are interested in people's experiences, ways to further tailor support or improve services.
- **Measure after an initiative** if you are interested in people's experiences and reflections about change. Sometimes it is helpful to measure immediately after people use services, when experiences will be fresh in their minds. At other times it may be more helpful to allow time to pass so people can reflect or can properly trial doing something differently. If you are interested in people's immediate perceptions, measure straight away. If you want to know whether changes are maintained, you could follow up after one month, six months or a year. Combining immediate and follow-up feedback often works well.
- **Measure before and after an initiative** if you are interested in monitoring changes or progress over time.

Allow enough time to test your approach

Set aside enough time and resources to test how you will measure – a pilot test or 'run through', particularly if you are planning to use your measures for many years or monitor changes over time. Testing also helps to check your approach is easy to understand and acceptable to a diverse range of people.

Make sure everyone is trained and informed

What training and resources do your team or workforce needs to get the most out of measuring? You will not get useful information if team members do not use a measure consistently or do not know how to implement the tool in daily practice. Perhaps introduce the tool at a staff meeting or in a short video, rather than relying solely on written information.

Plan how information will be analysed and shared

Make sure you have enough time, technology and appropriate staff to analyse and use the information you collect. Think about how the end result needs to be presented for various audiences, including the people you are supporting. Box 9 shows how one team shared their learning. This is an important and often overlooked stage.

Box 9: Sharing the learning from measuring

People with long-term dizziness are more likely than others to fall and be anxious about falling. A team in the South West distributed a self-management booklet about eye movement and physical exercises to retrain balance, made available in several languages.

Before people received the booklet, after three months and after six months the team measured:

- surveying people about their self-reported symptoms and quality of life
- observing how stable people were when standing
- reviewing service use figures about admissions for falls
- analysing the costs saved from fewer visits to primary care and hospital

and compared the findings with those for a group who did not receive the booklet. People who received the booklet said they had fewer symptoms and better quality of life.

The team made sure that the information was used to help individuals and shared widely with support services. They:

- used surveys as screening tools to discuss other support individuals wanted
- discussed learning at monthly team meetings and at public webinars
- promoted what they found in magazines, on blogs and in videos
- sent paper and electronic copies of the booklet to professionals and voluntary and community groups around the country.

Summarising your plans

Writing down your approach in a measurement plan can concisely bring all your decisions together. A measurement plan sets out what you will do to measure supported self-management, when, how and who will do it. It can be a simple table listing what to measure and when (see Figure 4 for an example). This works whether you are using measures to tailor support for individuals or evaluating supported self-management initiatives or systems.

Figure 4: Example simple measurement plan table

What do you want to achieve?	What will you measure?	How will you measure?	When will you measure?	Resources needed	Who will be responsible?

Appendix 1: Examples of what you could measure

Why are you measuring?	Example	What could you measure?	How could you measure?
Measures related to people you are supporting			
To understand the support needs of a **population** group	An integrated care system (ICS) wants to understand whether people from minority ethnic groups are more or less likely to exercise than other people and why	• Goals and needs of the population group • Motivation and confidence to self-manage • Self-management behaviours • Health literacy (understanding health information)	• Surveys • Interviews • Focus groups • Clinical records and biometric data • Service use data
To find out what an individual **needs** and what type of support might help	A nurse would like to understand how a person is managing their arthritis, what their goals are and how best to support them to achieve those	• People's individual goals and needs • Preferred types of support • Motivation and confidence to self-manage (activation) • Self-management behaviours • Health literacy	• Surveys • Interviews/structured conversations
To know if people have the knowledge, skills and **confidence** to self-manage well	A voluntary sector service wants to see whether a child with cancer knows how to keep themself feeling as well as possible	• Knowledge, skills, motivation and confidence to self-manage • Health literacy	• Surveys • Interviews
Measures related to professionals or systems			
To see whether professionals or systems are **supporting** self-management	A general practice wants to know whether people using services feel that doctors and nurses are listening to and encouraging them to reduce or give up smoking	• Professionals' attitudes towards supported self-management • Professionals' behaviours/activities • Number of support activities • Service user perceptions of support	• Surveys • Interviews • Observing consultations • Review of records • Review of policies
Judging the impact of **initiatives to help**	A local authority wants to know if an e-learning module helps social	• Professionals' attitudes • Professionals' knowledge and confidence	• Surveys • Interviews

Why are you measuring?	Example	What could you measure?	How could you measure?
professionals or systems better support self-management	services support people to self-manage their mental health	- Professionals' behaviours to support self-management - Number of activities - Patients' perceptions of support	- Observation of encounters - Records of types of support available
Measures related to supported self-management approaches			
Exploring whether people had a **good experience** of a self-management initiative	A voluntary sector organisation wants to know whether people were satisfied with their health coaching sessions	- Satisfaction, such as whether people would recommend to others - What people thought worked well and what could be improved	- Surveys - Interviews - Focus groups
Improving self-management support initiatives	An ICS wants to know why so many people with COPD stop using a digital symptom diary and telehealth system. It wants to make improvements and monitor the dropout rate	- Recruitment and implementation processes - Costs - Satisfaction - Suggestions for improvement - Measures of impacts such as experience, behaviours and clinical outcomes	- Surveys - Focus groups - Interviews - Observation - Document review
Judging the **impact** of an initiative on people's health, wellbeing or behaviours	A peer support group wants to measure the proportion of participants whose blood pressure is within a healthy range after three months	- Clinical indicators such as blood pressure or blood sugar control - Self-reported functional status - Self-reported quality of life or wellbeing - Self-management behaviours - Survival and morbidity - Use of health or care services or medicines	- Review of clinical or prescribing records - Physical activity tracking or biometric measures, eg using wearable devices - Surveys before and after the initiative - Interviews
Comparing and **prioritising** different support initiatives	A training hub wants to decide whether to continue with face-to-face training in health coaching or to do this online	- Process or impact measures relevant to the initiative - Costs such as cost per participant or cost per 'success'	- Surveys - Focus groups - Interviews - Review of records/clinical indicators - Service use data - Cost analysis

Appendix 2: Advantages and challenges of common measurement methods

Method	Advantages	Challenges
Clinical records, biometric data and service use data	• Can compare over time • Uses standardised coding • Already routinely collected • Provides data about longer-term changes	• May be difficult to access for those who are not part of the individual's care team • May not be sensitive to changes as a result of supported self-management
Content analysis of existing documents or online feedback	• Relatively quick and easy to do as draws on existing information	• Unlikely to be generalisable • May not be targeted at what you are interested in measuring
Survey questionnaires and scales	• People can provide anonymised feedback • Relatively inexpensive • Able to track changes over time if used consistently • Can be done online, via email or text as well as using kiosks, paper or structured telephone calls • Can reach a large number of people • Free tools are available for building and hosting surveys • Many validated survey scales are available, including some that are free to use • Can use visual elements	• May not gather detailed feedback on people's experiences, attitudes or behaviours • Only accessible to those able to read and write in the survey language • Not always accessible for children or people with a learning disability • Question wording and format can influence people's responses • People are often asked to complete surveys so can tire of doing so • Validated scales can be long or may not use language or questions appropriate to your needs
Interviews	• Able to probe for detailed information • Can be interactive and change focus based on what people say • Can be done in person, by telephone or online	• Can be time-consuming to organise, conduct and analyse • Can take more effort to draw out themes and compare data compared to surveys • Difficult to include in patient notes • Interviewer characteristics and style can influence feedback
Focus groups	• Can obtain detailed impressions from a group of people in a shorter time than individual interviews • Can hear how people react to the views of others • Can be done virtually or in person	• Can take time to organise • Can be challenging to draw out themes • People may not feel comfortable disagreeing with each other • Does not give data for individuals
Observation of self-management support or behaviours	• Collects first-hand experience of how something happens • Observer can see things that those running the activity may be unaware of	• Can be difficult to analyse and interpret • Can be time-consuming • Presence of an observer can influence behaviours

Appendix 3: Survey tools for use in supported self-management

Focus area	Surveys/scales	Tool description
Self-management needs and behaviours	Diabetes Self Management Questionnaire	- Focuses on people with diabetes - 16 items focused on blood sugar management, dietary control, physical activity and healthcare use - Available in multiple languages. Developed in Europe - Can be used as an individual assessment tool or measure to track progress before and after an intervention
	Long-term conditions questionnaire	- Explores impact of long-term conditions on people's lives and the individual support they want or need - 20-item tool developed in the UK - No cost
	Physical activity scale	- Various tools to measure whether people are taking part in self-management behaviours, such as eating healthily and being active - Can be used to identify the support behaviours and needs of individuals or groups, or to assess change after interventions - No cost
	Self-Management Assessment Scale	- Tool to help a person self-assess their self-management strengths, needs and possible barriers - Focuses on knowledge, goals for the future, daily routines, emotional adjustment and social support - Can be used in conversations with professionals - Can be used to tailor support for individuals or to measure change after an intervention - Tested in various parts of the world and with people with different conditions - No cost
Health literacy* (ability to obtain, read, understand, and use healthcare information)	Single Item Screener (SILS)	- Single question that can be added to other questionnaires - Asks how often a person needs someone's help when they read health information. Usually used as a one-off assessment rather than a before and after measure - Needs to be sensitively administered and may be most helpful when used in conjunction with techniques such as teach back. - No cost - Many other longer health literacy tools are available
	Newest Vital Sign (NVS)	- People are given a food label and asked 6 questions

Focus area	Surveys/scales	Tool description
		- Available in English and Spanish - Short. Takes 3 minutes. Designed for one-off use - No cost
Enablement/activation	Consumer Health Activation Index (CHAI)	- Examines knowledge, self-efficacy, beliefs, activity and locus of control - Can be used as an individual assessment tool to help tailor support or a measure of impact after an intervention - No cost; requires registration
	Patient Activation Measure (PAM)	- 10 or 13-item scale categorises people into four levels of activation or readiness to self-manage - Case studies and summary of evidence are available on the NHS England and NHS Improvement website - Mainly used as an individual assessment tool. Can be used before and after interventions
	Patient Enablement Instrument (PEI)	- 6-item scale exploring whether enablement improves following a primary care visit - Used at one point in time; people are asked to reflect on whether things are much better, better or the same or not as good following a consultation - Three items from this are used in the General Practice Assessment Questionnaire so it may be possible to draw on existing data at population level - No cost
Self-efficacy (extent to which a person believes in their ability to self-manage)	Chronic disease self-efficacy	- 6-item scale validated in many languages - Developed in the US so wording may need to be adapted for use in the UK - No cost
	Self-Management Screening Tool	- 27 items about self-efficacy, whether people feel they control what happens to them, depression, anxiety, coping, social support and burden of disease - Developed in Europe - Mainly used to tailor individual support but can be used as before and after measure - No cost
Wellbeing/health status quality of life	EQ-5D	- Short tools to measure quality of life, including mobility, self-management, usual activities, pain and anxiety - Available in over 200 languages and various formats - Can be used as before and after measure - Widely used so can compare with other initiatives
	Personal Wellbeing (ONS4)	- Used in the Office for National Statistics' Measuring National Well-being (MNW) Programme

Focus area	Surveys/scales	Tool description
		- Asks people to evaluate how satisfied they are with their life overall - Used by some UK social prescribing link workers when they start working with people and at a later point. Some other areas use Outcomes Star which is a set of visual tools, including those for young people
	PROMIS	- Many domains to choose from, including physical health, mental health and social health/isolation - Includes scales for adults and for children - Can be used as before and after measures - Developed in the US - No cost
	Self-rated health scale	- Single item validated tool used in US national surveys - Asks people to rate their health out of 5 - Can be used as a before and after measure - No cost
	Short Warwick-Edinburgh Mental Wellbeing Scale	- Used for both populations and individual interventions - Short. Validated in several languages - Need to register to use, but no cost
	Pain visual scale	- Example of visual scale to help people assess pain - Can be used to track change over time
Extent to which professionals or systems support self-management	Practices in Self-management Support	- Developed in the UK to measure clinicians' self-reported use of supported self-management practices in consultations
	Clinician Support for Patient Activation Measure (CSPAM)	- Explores professionals' attitudes towards using PAM tool - Used in the UK and internationally
	Assessment of Primary Care Resources and Supports for Chronic Disease Self-Management	- Developed by a group focused on diabetes, but can be used more broadly in primary care - Designed to track progress in organisations over time - Developed outside the UK so wording may need to be adapted. - Online version available

Focus area	Surveys/scales	Tool description
	Patient Assessment of Care for Chronic Conditions (PACIC)	• 20- and 26-item scales developed in the US • Looks at variety of elements of care. Supported self-management is one element

* As between 43% and 61% of the working age population in England do not routinely understand the health information they are given (Institute of Health Equity/Public Health England 2015), a Universal Precautions approach (based on using simple language, checking understanding and avoiding the use of medical jargon and acronyms) rather than a measurement approach is generally recommended in most situations.

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