Service user participation strategy 2021-2023

Health and Social Care

Sue Ryder

palliative,
neurological
and bereavement
support

Sue Ryder service user participation strategy 2021-2023

Introduction

The people we support are at the heart of what we do as an organisation, those with life limiting and neurological conditions, those important to them and those who are bereaved. We are committed to ensuring that everyone who accesses Sue Ryder services is listened and responded to, so that they receive high quality, personalised care. The Charity's five year strategy, 2018–2023 strives to deliver more care to more people, and involvement of service users is key to our success.

Service users have a unique contribution to make as they are experts by experience in addition to any other skills, qualities or knowledge they have. Their voices, experience and support, shape and direct our activity across health and social care: this is evident in our approach to quality improvement and in our influencing and policy work. We recognise the need to expand our service user participation to other activities such as recruitment, service planning and delivery, and assuring the quality of our services.

The service user participation strategy outlines our commitment to ensuring service user participation is embedded throughout our services. It sets out our objectives, plan and measures for the participation of service users across Sue Ryder.

What we mean by service user

A service user is defined, in this strategy, as someone who is using or has used our services. Some people may wish to identify themselves by other terms, such as 'patient', 'client', 'expert by experience', 'member', etc. This will be respected in the course of working with individuals or groups. The term 'service user' includes families and informal carers.

In the longer-term our intention is to encourage greater participation not only from the communities in and around our neurological, palliative and community-based services but across local boundaries. This will ensure that our services develop to meet the needs of the populations we support in the future.

What we mean by participation

We want service users to actively take part in the activities of the organisation from shaping the support they receive, taking part in the recruitment of staff who support them, to working alongside staff on the development of services.

It is about making sure that the views of the people who use our services have the chance to be heard in order to make real, sustainable changes. Quite simply, by making sure that the voices of our service users are heard, we will ensure that they are able to have a genuine influence on the support they receive and the services we provide.

Levels of participation are often described as a 'ladder of participation', developed by Sherry Arnstein (1969) to demonstrate that differing levels of participation may be appropriate for different situations and for different people. The NHS adapted the Arnstein model for their 'Ladder of Engagement and Participation'[1] creating the levels of 'Informing' to 'Devolving'. The NHS levels will be used for this strategy but the descriptions have been adapted to be more relevant to Sue Ryder.

Sue Ryder Ladder of Participation

Devolving	The focus is user-led. Decision-making, responsibility and power is devolved to service users.
Collaborating	Service users and staff work together from design to delivery, sharing decision-making about policies as well as decisions about the best way to deliver services. The service user has genuine influence. E.g. designing a service based on service user experience, co-investigator on a research project.
Involving	Service users are given opportunities to express their views, concerns and aspirations in more detail which may influence some decisions. E.g. service user involvement at Quality Improvement Groups.
Consulting	Seeking the views and opinions of service users on services, policies etc. which is taken account of in decisions. E.g. surveys and user groups.
Informing	Letting service users know what our services are and how they work. Informing service users of what decisions have been made and why. E.g. a leaflet.

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[1] https://www.england.nhs.uk/participation/resources/ladder-of-engagement-2/

The ladder of participation will be used to assist our services in measuring and reporting levels of participation. Services will establish a baseline of current levels of participation using self-assessment and develop local action plans which will be monitored on a regular basis by the local Quality Improvement Group and through quarterly performance reviews.

Why we want to increase participation

Some of the national drivers for greater service user participation are outlined in:

- The Care Quality Commission (CQC) Strategy 2016 to 2021 - ‘Shaping the Future’
- The Scottish Care Inspectorate Corporate Plan 2019 to 2022

The Scottish Care Inspectorate clearly state that Scotland’s Health and Social Care Standards will help everyone focus on what really matters – the experience of the person who uses care. The standards will also help shape the way in which care is designed and delivered in the future. The standards are underpinned by five principles – dignity and respect, compassion, be included, responsive care and support and wellbeing – and they are based on five headline outcomes:

- I experience high quality care and support that is right for me
- I am fully involved in all decisions about my care and support
- I have confidence in the people who support and care for me
- I have confidence in the organisation providing my care and support
- I experience a high quality environment if the organisation provides the premises

The CQC sets out an ambitious vision for a more targeted, responsive and collaborative approach to regulation, so that more people get high-quality care. Furthermore, the strategy highlights that quality cannot be assessed from data alone but by bringing together information from people who use services and their carer’s knowledge through their inspections.
They state that the public and people who use services have a crucial role to play in improving quality by sharing their experiences of care and speaking out when it needs to improve.

The NHS Patient experience improvement framework stated in June *2018 “Patients also have a positive experience where there is a culture of safety across an organisation that puts the patient first and gives patient experience the highest priority with the implementation of real-time patient feedback. Information about real-time patient experience displayed on all wards and clinic areas gives added evidence of priority. A culture of ensuring lessons are learnt from complainants’ feedback can be used to improve services.”*

At Sue Ryder we put those we care for at the heart of all our activities. But in the drive for continuous improvement, we also believe we can do more to ensure participation and engagement for all our service users, which is why we have this strategy in place.

Our principles for increased service user participation

In the development of the service user participation strategy, we consulted, listened, engaged and learned from our service users, their families and our staff. This has resulted in a set of principles to shape participation.

1. Embedding service user participation is the responsibility of everyone in the organisation.

2. Service users participate fully in the development, implementation and embedding of the service user participation strategy at a local level. Local plans are built on service user feedback and detail how service users participate in ongoing service improvements and developments.

3. There is equity and fairness in how individual service users participate, especially for those who find it hard to communicate.

4. Staff have the right training skills and capabilities to work with service users and their informal carers to make the most of their participation. Service user experience is embedded in all aspects of leadership development.

5. Standards are adhered to and based on current and emerging best practice. Where appropriate external working relationships and partnerships regarding service user participation will be fostered.

6. Service user experience is integral to all levels of clinical governance and fully aligned with quality improvement.

7. Processes are in place to safely facilitate all forms and at all levels of service user participation.

8. Service-specific targets and outcomes to monitor and evaluate participation are agreed and regularly reviewed.

How we currently engage people

There are many excellent examples of how we currently engage our service users throughout Sue Ryder:

- **Regular local user group meetings** at our hospices and neurological care centres are where service users and carers meet with management teams to focus on and discuss key activities and projects to improve our local services. Service users are also invited to join the Quality Improvement Group meetings.
- **Real-time feedback** has been implemented across all our services. This allows the Senior Management team to review the feedback in "real-time" and address any issues or concerns in a timely way.
- **You said, we did boards** are displayed in our hospices and neurological centres to clearly explain the improvements we have implemented as a result of service user feedback.
- **Surveys, comment cards and complaint reporting** actively seek feedback from all our service users and families. All the feedback received is used to drive improvement in the care we provide and the services we deliver.
- **Spot checks** are employed in our Homecare services in Scotland giving service users the chance to feedback either face to face or by phone. We also utilise self-addressed postcards for service users and their families to complete at their convenience.
- **Quality visits** are conducted over two days at all of our hospices, Homecare services and neurological centres. We seek feedback from service users and relatives regarding the care and services they receive. The Quality and Governance team undertook Human Rights training to underpin the skills and techniques used during quality inspections.
- **Encouraging service users and families to shape our influencing work.** This takes a number of forms, for instance, consulting with online community members regarding bereavement support to inform our evidence to the House of Commons Work and Pensions Committee, or holding consultation events with Healthcare Improvement Scotland for service users and family members to shape the national standards on neurological care.
- **Case studies.** Sue Ryder has a dedicated Case Study Manager to curate and collect case studies from staff and service users across the organisation. The CSM conducts one-to-one interviews with service users or their relatives, giving them the opportunity to reflect and feed back on the care and support they have received from Sue Ryder.

Case studies are used to inform decision-making processes and assist in raising awareness and funds for the organisation.

- **Research and user involvement.** Service users and families work with us on research projects from advising on the best way to conduct studies, to being co-investigators.

Through this strategy we will create more systematic and structured opportunities for service users to participate throughout Sue Ryder.

How we used feedback from service users to deliver continuous improvement

Hospital passports

We have used feedback to continue our approach to care planning in neurological and homecare services to ensure they are person-centred and user driven. This has included implementing a hospital passport for every service user. The purpose of the hospital passport is to record all the important information about that person, reducing the time needed to provide support and treatment. This is particularly important for those with complex communication difficulties and whose complex care needs may mean that their non-verbal communication or challenging behaviour could be misinterpreted.

Furnishing and decor

Service users have been actively involved in the choice of furnishings and the decoration of their environment in our palliative and neurological centres and day hospices. Service users have also been involved in the design of our extension at Dee View Court and in the new Lancashire Neurological Centre.

Leaflets

Service users have been involved in the production of welcoming material for all new service users that come to our hospices and neurological centres. All our healthcare leaflets that have been developed are reviewed by service users.

Recruitment

At our neurological centres, candidates have met with service users as part of the interview process and feedback from the service users has influenced the outcome.

Online Community

A focus group was consulted on what our Online Community should offer, shaping how it was developed.

Mealtimes

As a result of feedback from service users the mealtime experience was improved, for example, taster sessions are offered to residents in our neurological centres, chefs in our hospices discuss individual dietary requirements with patients daily and where service users require a liquidised diet staff ensure that it is presented in an appetising way.

PR work

The PR team have asked questions in the Online Community to help inform and influence campaign activity. For our Just Say Something campaign in February, we asked the Online Community about their experience of what helped them when they were bereaved, which gave us qualitative data to go alongside our survey results.

Our aim

Our aim is to deliver partnerships which put service users' views, needs, aspirations, experiences and expert knowledge at the heart of what we do; participating in how we run, change and influence the development of our services.

To achieve this we will embed a culture of participation giving staff, volunteers and service users the knowledge and confidence to work together, ensure the service user voice is incorporated in all that we do and extend participation so our services reflect the needs of the populations we support.

Outcomes

- Our staff, volunteers and service users have the knowledge and confidence to work together.
- The service user voice is evident in all that we do and influences change.
- Our services reflect the needs of the populations we support now and in the future.

Measuring our success

Participation should be meaningful and measured not only by the extent to which people feel they have been involved but by how service user participation results in changes and improvements to people's lives and our services.

There are 3 areas of measurement:

Baseline: We will establish a baseline level for each of our palliative, neurological and homecare services measuring against the ladder of participation. Progress will be reported through the Integrated Quality and Performance monitoring process with visibility at the Healthcare Governance Group and Health and Social Care Sub-Committee.

Outputs and outcomes: We will measure the increase in opportunity to participate and the benefit to individual service users, staff and the organisation of that participation. Implementing a process to capture feedback on the experience from all those involved will ensure continued engagement and encouragement of others to participate.

Evaluation: We will evaluate the implementation of the strategy in the following way:

- **Method of participation** – review the different ways service users have participated identifying what works best and what requires improvement.
- **Level of satisfaction** – understand the experience of participation for all those involved.
- **Extent of change** – demonstrate the difference participation has had on individuals and the organisation.

Achieving our outcomes

The following tables provide an overview of the actions, activities and measures we will implement to achieve our strategic outcomes.

Achieving our outcomes – an overview

Outcome	**Our staff, volunteers and service users have the knowledge and confidence to work together**	**The service user voice is evident in all that we do and influences change**	**Our services reflect the needs of the populations we support now and in the future**
Actions	Raise awareness of the strategy across the Charity reaching staff, volunteers, service users and their informal carers. Develop our staff and volunteers to ensure they know how to work with service users and their informal carers to make the most of their involvement. Establish an Expert by Experience Committee.	Develop opportunities for participation in activities: • recruitment and training, • staff appraisals and professional revalidation • research, • shaping and developing our services. Develop mechanisms to gather feedback on our services at the point of care (real-time) and to report how it influences service delivery. Embed mutual feedback to reflect and learn from participation.	Develop participation opportunities for people in the communities in and around our services and beyond local boundaries. Develop an inclusive and diverse Expert by Experience register, reflecting the populations we support. Develop external working relationships and collaboration partnerships regarding service user participation.

Outcome	**Our staff, volunteers and service users have the knowledge and confidence to work together**	**The service user voice is evident in all that we do and influences change**	**Our services reflect the needs of the populations we support now and in the future**
Activities	A communications plan that raises awareness of the strategy across the Charity. Regular ‘stories’ to raise awareness of and encourage participation. A training programme to build confidence and knowledge of staff, volunteers and service users. Terms of reference for Expert by Experience Committee.	Define distinct roles and responsibilities for service user participation. Develop guidelines on participation, the expectations, roles and opportunities available. Update existing documentation (where appropriate) to reflect service user needs and evidence contribution e.g. terms of reference for committees, business case templates etc. Implement a process where service users can give and receive feedback on their experience of participation.	Review potential for developing a Register of people interested in participating in the organisation’s activities. Develop a recruitment process to the register for those who have expressed an interest in participating. Identify gaps in representation to ensure equity and fairness. Identify local and national bodies/organisations with potential for collaboration. Develop processes to access external feedback.

Outcome	**Our staff, volunteers and service users have the knowledge and confidence to work together**	**The service user voice is evident in all that we do and influences change**	**Our services reflect the needs of the populations we support now and in the future**
Measures	These will include quantitative measures on the number and proportion of staff completing training and the proportion who feel their knowledge and confidence has increased over time. Qualitative measures will include examples of how: • Opportunities to participate are communicated to service users. • Feedback is shared with those who have contributed (e.g. 'You said, We did', noticeboards etc.) • Awareness training has changed the outlook and behaviour of staff. • Service users were supported to make best use of opportunities to participate. • The Expert by Experience Committee has influenced participation.	These will include quantitative measures on the number of service users who have participated and in what types of role e.g. design / development of services, research, recruitment, appraisals etc. Qualitative measures will include examples of: • What has changed as a result of participation • In what capacity service users were involved. • How their involvement influenced or supported the outcome. • Service user feedback	These will include quantitative measures on the number of service users on the register and by demographics to ensure equity and fairness. Qualitative measures will include examples of: • How external feedback has influenced our service offer. • How working with external organisations has influenced how we develop participation.

Conclusion

This strategy has been produced with the involvement of our service users, families and staff at our palliative and neurological centres and homecare services. It clearly demonstrates our passion and commitment to continuously improve our service user experiences in all our services and use their "voice" in our influencing work, service development and quality assurance. This strategy is for the next three years and will continue to be reviewed against Sue Ryder's strategic objectives during this time to ensure it remains aligned.