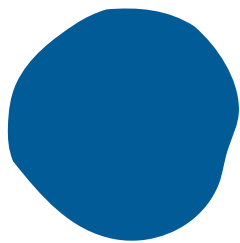


Sue Ryder

Service user strategy 2015-18



Introduction

People with life-limiting and neurological conditions are at the heart of what we do as an organisation. Their voices, experience and support, shape and direct our activity across health and social care: evident in our approach to quality and our campaigning and policy work.

We recognise that to ensure everything we do is underpinned by our values, there is work to do to increase service user voice and participation.

Our values:

- Do the right thing.
- Push the boundaries.
- Make the future together.

As part of our review of service user involvement, and to develop our strategy in this area for the next three years, we have listened, engaged and learnt. This has resulted in a series of aims and measurable objectives which are nationally owned and monitored whilst being locally shaped and implemented by communities in and around our neurological, palliative and community-based services.

What do we mean by involvement?

Within Sue Ryder we define service user involvement as 'activity that enables users of services to influence decision-making and actions taken at all levels within the organisation.'

Our aim

We are committed to ensuring that everyone who accesses Sue Ryder's services is listened and responded to, so that they receive high quality, personalised care.

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

This strategy outlines our commitment to ensuring service user involvement is embedded throughout health and social care.



Our objectives for increased service user involvement

We developed our objectives by working with our national service user group, 'Acorns'. These have been further shaped and developed with a range of service users from all service areas at a series of workshops in each centre, site and community forum.

Our objectives:

1. To use an overall Sue Ryder service user strategy to shape and direct service-specific implementation plans.
2. To ensure service user engagement in recruitment and training in all front line areas.
3. To ensure there is equity and fairness in how individual service users participate in service user involvement, especially those who find it hard to communicate.
4. To develop staff and service user support and training to ensure barriers are reduced.
5. To develop our staff to ensure they know how to work with service users and their informal carers to make the most of their involvement (this training is likely to extend to the Fundraising and PR Teams).
6. To develop standards of good practice and service-specific targets and outcomes for participation within individual service plans so these can be monitored and evaluated.
7. To ensure local plans outline how service users are involved in local centre management decisions regarding developments.
8. To introduce a Trustee role with special interest in service user involvement within the Board of Trustees.
9. To introduce service user involvement with staff appraisals and to introduce service user feedback into Nursing and Midwifery Council portfolios for registered nursing staff.
10. To research and develop more ways for service users to have their voice heard in a timely way, building on real-time feedback.
11. To develop a process for service users to be involved in shaping and developing our policy and campaigning work.

See Appendix 1 for the results of the service user priority setting and comments received.

Why do we want to involve people?

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

- The Care Quality Commission (CQC) Strategy 2013 to 2015 - 'Raising standards, putting people first'
- The Scottish Care Inspectorate Corporate Plan 2014 to 2018, strategic objective three - 'to ensure service user voice is heard and acted upon'

Healthwatch England was set up in October 2012 to make sure that the views and experiences of people who use health and social care services are heard and taken seriously at a local and national level. CQC inspection teams and the local Healthwatch share information to ensure this happens in practice.

Publicly, the most important driver for involving service users is the expectations of care.

"There must be real involvement of patients and the public in all that is done."

- Robert Francis in his published report in November 2013 following the Mid Staffordshire NHS Foundation Trust Public Inquiry.

The report states that the values and standards within any healthcare organisation must be underpinned by a common patient-centred focus which produces and upholds fundamental standards of care.

He also recommended a number of measures regarding information, stating:

"[Information] is the life blood of an open, transparent and candid culture and should be used to improve the experience of patients and staff."

Organisationally, we have responded to the Francis report in a number of ways:

- Strengthening our focus on quality and safety
- Building a strong nursing voice and clinical leadership
- Transparency in the management of complaints
- Developing a culture where there is a clear focus on the individual and a personalised approach to care

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 service users, which is why we are putting this strategy in place.

How do we currently involve people?

We currently involve and engage our service users through a number of different channels throughout Sue Ryder:

- **Regular local user group meetings** at our hospices and neurological care centres where service users and carers meet with management teams to focus and discuss key activities and projects to improve our local services.
- **Our national user group, 'Acorns'** was established in 2010 and has service users from both our palliative and neurological services meeting three times a year. This group is active in supporting the recruitment of executive and senior health leaders within the organisation. It is also active in shaping our Quality Account, which identifies areas for improvement across all service areas. Attendance at Acorns includes members of the Executive Leadership Team and Trustees, ensuring that feedback is acted upon.
- **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 to our care and services.
- **Real-time feedback** has been piloted in a number of areas and we plan to roll this out across all service areas in 2015-16. We will be supporting and training our volunteer workforce to assist with real-time feedback for those using our services (allowing greater opportunity for honest feedback).
- **Spot checks** are employed in our homecare services in Scotland giving service users the chance to feedback either face to face or on the 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, across all the hours the service operates (including nights). We seek feedback from all service users and relatives regarding the care and services they are receiving. The Clinical Quality Team also undertook Human Rights training to underpin the skills and techniques used during quality inspections.
- **Encouraging service users and families to get involved with our national campaigns**, influencing the Government by sharing their experiences. A number of service users have attended national conferences and key debates in the Houses of Parliament to provide a detailed account of their experiences, bringing alive the impact of service configuration and policy implementation.

How have we used this feedback and involved service users to deliver continuous improvement?

- **Hospital passports**

We have used feedback to make our care planning in neurological and homecare services person-centred and user driven. This has included developing and 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.

- **Shaping publications and standards of care**

The national serviceuser group 'Acorns' and quality leads throughout the charity have developed the mealtime and 'B-Active' standards as a direct result of user feedback. This has been implemented in all our Sue Ryder services.

The "How to complain" leaflet was reviewed by Acorns to ensure it is accessible to all. This has been developed alongside training for staff on how they can support service users to provide both constructive and positive feedback, within a culture which encourages feedback.

- **Furnishing and decor**

Service users have been actively involved in the choice of furnishings and the decoration of their environment in our neurological centres and day hospices.

- **Responding to consultations**

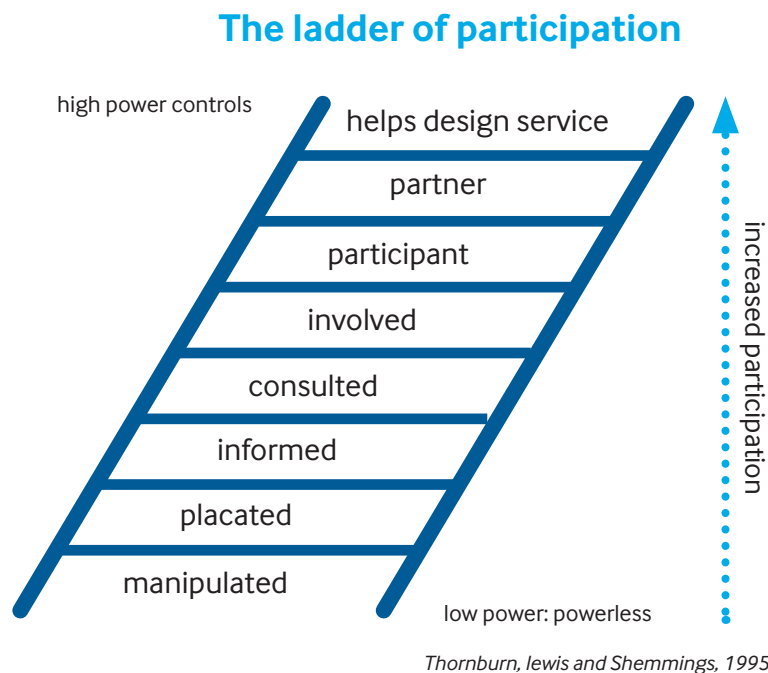
Service users have used their voices externally in responding to consultations, for example from the Care Quality Commission and Continuing Care Inquiry. At a local level the Marketing Team has worked with service users to produce material which reflects their opinions and voice.



Action plan

Our national strategy shapes and directs our approach to service user involvement, whilst allowing flexibility at local level. This will enable service users to influence decision making and actions taken at all levels within the organisation. It will support our Policy and Campaigns Team by giving a clear voice to policy issues which affect people who use our services on a regular basis.

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:



Participation 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.

The ladder of participation will be used to assist service areas in measuring and reporting levels of participation. It will be self-assessed at the start point for individual service areas then actions and progress will be monitored on a regular basis by the local Quality Improvement Group and reported in quarterly performance reviews. This approach of self-assessment and measurement will demonstrate to patients, their families and regulatory bodies that our services are shaped and driven by experience.

See Appendix 2 for the national implementation and action plan and **Appendix 3** for the local implementation and action plan template.

This strategy has been produced 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.

Appendix 1: results of the service user priority setting and comments received

Hospices

The following table provides the collective data on the questions asked:

| Please indicate if you strongly agree, agree, neither agree nor disagree or don't agree with the following proposed objectives for service user involvement: | Strongly agree | Agree | Neither agree or disagree | Don't agree | % total strongly agree and agree |
|--|----------------|-------|---------------------------|-------------|----------------------------------|
| To ensure that everyone has the opportunity via different methods to share their opinions, ideas and views to help shape our services. | 17 | 1 | 0 | 0 | 100% |
| To ensure service user engagement in recruitment and training in all front line areas. | 15 | 2 | 1 | 0 | 94% |
| To ensure there is equity and fairness in how individual service users participate in service user involvement, especially those who find it hard to communicate. | 15 | 3 | 0 | 0 | 100% |
| To develop staff and service user support and training to ensure barriers are reduced. | 13 | 4 | 1 | 0 | 94% |
| To develop our staff to ensure they know how to work with service users and their informal carers to make the most of their involvement (this training is likely to extend to the Fundraising and PR Teams). | 12 | 2 | 3 | 0 | 78% |
| To develop standards of good practice and service-specific targets and outcomes for participation within individual service plans so these can be monitored and evaluated. | 6 | 7 | 4 | 0 | 72% |
| To use an overall Sue Ryder service user strategy to shape and direct service specific implementation plans. | 9 | 3 | 4 | 1 | 66% |
| To ensure local plans outline how service users are involved in local centre management decisions regarding developments. | 11 | 3 | 2 | 0 | 78% |
| To introduce service user involvement with staff appraisals and to introduce service user feedback into Nursing and Midwifery Council portfolios for registered nursing staff. | 11 | 4 | 3 | 0 | 83% |
| To research and develop more ways for service users to have their voice heard in a timely way, building on real-time feedback. | 12 | 3 | 3 | 0 | 83% |

| Please indicate if you strongly agree, agree, neither agree nor disagree or don't agree with the following proposed objectives for service user involvement: | Strongly agree | Agree | Neither agree or disagree | Don't agree | % total strongly agree and agree |
|---|-----------------------|--------------|----------------------------------|--------------------|---|
| To agree what user involvement at Sue Ryder central board level looks like. | 5 | 6 | 1 | 0 | 61% |
| To develop a process for service users to be involved in shaping and developing our policy and campaigning work. | 7 | 4 | 1 | 0 | 61% |

Neurological care centres

The following table provides the collective data on the questions asked:

| Please indicate if you strongly agree, agree, neither agree nor disagree or don't agree with the following proposed objectives for service user involvement: | Strongly agree | Agree | Neither agree or disagree | Don't agree | % total strongly agree and agree |
|---|-----------------------|--------------|----------------------------------|--------------------|---|
| To ensure that everyone has the opportunity via different methods to share their opinions, ideas and views to help shape our services. | 19 | 3 | 2 | 1 | 88% |
| To ensure service user engagement in recruitment and training in all front line areas. | 19 | 4 | 2 | 0 | 92% |
| To ensure there is equity and fairness in how individual service users participate in service user involvement, especially those who find it hard to communicate. | 15 | 4 | 6 | 1 | 76% |
| To develop staff and service user support and training to ensure barriers are reduced. | 15 | 6 | 3 | 0 | 84% |
| To develop our staff to ensure they know how to work with service users and their informal carers to make the most of their involvement (this training is likely to extend to the Fundraising and PR Teams). | 16 | 5 | 3 | 0 | 84% |
| To develop standards of good practice and service specific targets and outcomes for participation within individual service plans so these can be monitored and evaluated. | 4 | 9 | 5 | 0 | 52% |
| To use an overall Sue Ryder service user strategy to shape and direct service specific implementation plans. | 9 | 9 | 7 | 1 | 72% |

| Please indicate if you strongly agree, agree, neither agree nor disagree or don't agree with the following proposed objectives for service user involvement: | Strongly agree | Agree | Neither agree or disagree | Don't agree | % total strongly agree and agree |
|---|-----------------------|--------------|----------------------------------|--------------------|---|
| To ensure local plans outline how service users are involved in local centre management decisions regarding developments. | 7 | 4 | 2 | 2 | 44% |
| To introduce service user involvement with staff appraisals and to introduce service user feedback into Nursing and Midwifery Council portfolios for registered nursing staff. | 10 | 5 | 4 | 0 | 60% |
| To research and develop more ways for service users to have their voice heard in a timely way, building on real-time feedback. | 3 | 7 | 6 | 2 | 40% |
| To agree what user involvement at Sue Ryder central board level looks like. | 6 | 10 | 4 | 1 | 64% |
| To develop a process for service users to be involved in shaping and developing our policy and campaigning work. | 7 | 8 | 4 | 1 | 60% |

Appendix 2: national implementation and action plan

| Sue Ryder value | Objective | Level of participation benchmark assessment (to be completed by the Quality Action Group) | Actions | Level of participation quarterly reassessment (to be completed by the Quality Action Group) |
|---------------------------------|---|--|---|--|
| Make the future together | Use an overall Sue Ryder service user strategy to shape and direct service-specific implementation plans. | | To share the Sue Ryder service user strategy with all service users. | |
| | Introduce a role of Trustee with special interest in service user involvement within the Board of Trustees. | | Opportunity to shape appointment of Trustee with special interest in service user involvement. | |
| Do the right thing | Develop our staff to ensure they know how to work with service users and their informal carers to make the most of their involvement (this training is likely to extend to the Fundraising and PR Teams). | | To work with the practice educator and service user group to identify what training would be beneficial and how this can be implemented. | |
| Push the boundaries | Research and develop more ways for service users to have their voice heard in a timely way, building on real-time feedback. | | <p>To implement different ways service users can have their voices heard.</p> <p>To implement real-time feedback into your service and unitise the feedback to continually make improvements for the service users.</p> | |

Appendix 3: local implementation and action plan

| Sue Ryder value | Objective | Level of participation benchmark assessment (to be completed by the service) | Actions (examples) | Level of participation quarterly reassessment (to be completed by the service) |
|---------------------------------|--|---|---|---|
| Make the future together | Ensure there is equity and fairness in how individual service users participate in service user involvement, especially those who find it hard to communicate. | | <i>Provide different methods for service users to share their opinions, ideas and views to help shape our services. (e.g. real-time feedback)</i> | |
| | Develop staff and service user support and training to ensure barriers are reduced. | | <i>Train staff and volunteers in communicating with those who experience communication difficulties.</i> | |
| | Develop a process for service users to be involved in shaping and developing our policy and campaigning work. | | <i>Facilitate active involvement in campaigns for those who want it. Workshop/link with Policy and Campaigns Team to link their work with service user voice.</i> | |
| | Ensure local plans outline how service users are involved in local centre management decisions regarding developments. | | <i>Outline the involvement service users will have, working together with the Centre Management Team.</i> | |

| Sue Ryder value | Objective | Level of participation benchmark assessment (to be completed by the service) | Actions (examples) | Level of participation quarterly reassessment (to be completed by the service) |
|----------------------------|---|---|---|---|
| Push the boundaries | Introduce service user involvement with staff appraisals and to introduce service user feedback into Nursing and Midwifery Council portfolios for registered nursing staff. | | <i>Develop different feedback channels for service users to provide feedback for staff appraisals and NMC portfolios.</i> | |
| | Develop standards of good practice and service specific targets and outcomes for participation within individual service plans so these can be monitored and evaluated. | | To measure and monitor the standards of good practice through your quality improvement plan, quality improvement meetings and your quarterly performance reviews. | |
| Do the right thing | Ensure service user engagement in recruitment and training in all front line areas. | | To identify the service users who would be willing to be involved in the recruitment and training of staff and how this would be implemented. E.g. development of virtual stories and video. | |

Sue Ryder provides incredible hospice and neurological care for people facing a frightening, life-changing diagnosis. It's not just expert medical care we provide. It's the emotional support and practical things we take care of too. We do whatever we can to be a safety net for our patients and their loved ones at the most difficult time of their lives.

Not only do we treat more conditions than any other UK charity in our hospices, neurological care centres and out in the community; we also campaign to improve the lives of people living with them. We see the person, not the condition, taking time to understand the small things that help that person live the fullest life they can.


For more information about Sue Ryder

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This document is available in alternative formats on request.

incredible hospice
and neurological care

*Calls cost 5p per minute plus your telephone company's network access charge.

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