

Evaluation of NCSI User Involvement Model

Final report

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Foreword from Macmillan Cancer Support

Macmillan champions the involvement of people affected by cancer in health and social care. The Macmillan User Involvement agenda puts people affected by cancer at the heart of service design and development; it focuses on the continuous improvement of what matters most from a user perspective; and empowers service users to innovate for wider patient and carer benefit.

From ‘entry level user involvement’ to the co-creation of service redesign, the Macmillan User Involvement agenda has sought to transform the way in which people affected by cancer are involved, as equal partners, in shaping cancer services.

It is in keeping with this ethos that Macmillan initiated an innovative approach to this research, which demonstrates the co-design of an evaluation framework involving service users. The NCSI User Involvement evaluation has, from the outset, been led by service users. Members of the NCSI service users peer support group worked with Macmillan and the researchers to define the scope and methodology underpinning the research.

Macmillan hopes that this research approach demonstrates how it works in partnership with people affected by cancer to evaluate national initiatives that it is involved in; demonstrating accountability, transparency and genuine rather than tokenistic involvement of people affected by cancer as ‘experts by experience’.

We therefore welcome this research report and we would particularly like to commend Papworth Research & Consultancy Ltd and *InHealth* Associates for ensuring that service users played an active role as co-researchers. The service users who took on the role of co-researchers played an instrumental role in shaping this research. We would like to thank them and the peer support group for their contribution.



Stephen Hindle

Cancer Survivorship Programme Lead, Macmillan Cancer Support

Executive summary

The NCSI

Formally launched in September 2008, and running until 2012, the National Cancer Survivorship Initiative (NCSI) aims to improve services and support for those living with, and beyond, cancer, to ensure that survivors get the care and support they need to lead as healthy and active a life as possible, for as long as possible. It is being delivered by Macmillan Cancer Support in partnership with the Department of Health.

Service User involvement in the NCSI

In phase one, from September 2008 to April 2010, seven NCSI workstreams were established to identify user needs and develop new models of care, to meet survivors' needs within current financial and workforce constraints.

The steering group and each of the above workstreams appointed two or three members who were Service Users (a mixture of patients and carers). In addition, some workstreams included health professionals who also had experience of using services.

The workstreams were wound up at the end of phase one. In phase two (April 2010 to September 2012), the NCSI consists of 30 projects aiming to test the new models developed through phase one.

The evaluation

Macmillan Cancer Support commissioned Papworth Research & Consultancy Ltd and InHealth Associates to evaluate user involvement in the NCSI. The aims of the evaluation were to investigate the following questions:

- What impact did user involvement have on NCSI workstream activity?
- What impact has user involvement had on the Service Users themselves?
- What were the barriers and facilitators to effective engagement of Service Users in each workstream?

Users were involved in the evaluation from the outset. The service users on the Peer Support Group worked with Macmillan Cancer Support to develop the tender, select the researchers and develop the model for the evaluation. Papworth Research & Consultancy Ltd and InHealth Associates provided training to, and worked with.

The evaluation methodology consisted of the following:

- A focus group attended by eight Service Users (all of whom also participated in one-to-one telephone consultations);

- 30 interviews as follows:
 - Telephone interviews with Service Users;
 - Face-to-face interviews with each of the seven Workstream Chairs;
 - Telephone interviews with Workstream Support Officers;
 - Telephone interviews with Other Workstream Members suggested by the Peer Support Group.

Findings

- Models of Services User involvement:
 - Interviewees reported that workstreams were not guided as to how to involve Service Users, despite the fact that Service User involvement was intended to be a central component of the initiative.
 - In the absence of a strong steer as to how to manage Service User engagement, workstreams each devised their own model of involvement, ranging from consultations, through implementation of project work, to active strategic involvement.
- Interviewees' perceptions of the Service User role:
 - Service Users and Chairs both felt that Service Users lacked clarity as to their role.
 - Given this lack of clarity, the role of Service Users seemed to have been determined by the circumstances of each workstream (such as the type of work it was doing, and the experience of other members of Service User engagement or of using services themselves).
 - Service users played a variety of different roles across workstreams to ensure work was 'patient-centred': from keeping workstreams focused on the 'holistic needs' of patients through to drawing on others' experiences.
 - Several Service Users felt under-valued, particularly with regard to their ability to draw on wider networks as well as report their own experience.
- Impact of Service User involvement on the NCSI:
 - Service Users were roughly equally divided as to whether or not they felt 'heard', though those that did feel 'heard' were unsure whether their input had made a difference.
 - Service Users at best thought that, although they had been listened to, their views had little impact and, at worst, thought they had not been heard.
 - Chairs and workstream members reported that Service Users had had an impact on the workstreams' activities. However, this varied across workstreams.
 - A few examples of the impact of Service User involvement were highlighted in some workstreams. These were defined in a variety of ways including the 'atmosphere' of involvement (e.g. increased trust and better relationships), improvements in the

process through which issues were taken forward (e.g. a pilot approach being developed differently) and issues that users worked on specifically (e.g. patient information).

- There seemed a striking difference in views between Service Users and other workstream members about whether users had been listened to and/or had had an impact.
- Barriers and facilitators to effective Service User engagement:
 - Several Service Users felt that they had been marginalised during this programme of work and that their value had not been recognized.
 - Creating clarity around the role of Service Users, and a shared understanding of this, would have improved both the experience of Service Users and their perception of any impact they had.
 - The way in which meetings were chaired was seen by Service Users as key to their experience and the extent to which they were heard. Most felt that the way meetings were chaired could have been improved, although a few reported that meetings **had** been effectively chaired, and Chairs reported ways in which they had sought to facilitate Service User engagement.
 - It is clear that greater transparency of the procedures by which Service Users were allocated to workstreams would have improved Service Users' experiences. They would have welcomed a formal induction process, and sharing biographies could have formed part of such a process.
 - There is evidence of communication breakdowns, with Services Users reporting that the changes as the NCSI moved into its second phase were not adequately explained to them and that some inter-workstream communications didn't reach them.
 - It appears that the structures for supporting Service Users were not always as effective as they might have been. Interviewees of all types reported lack of clarity over the role of the Peer Support Group, and lack of clarity over whose role it was to support Service Users
 - Some Service Users reported a lack of resourcing for their activities, learning & development opportunities and practical support.
- Skills needs:
 - Most Service Users and other workstream members felt that Service User impact would have been improved had Service Users been provided with further learning and development opportunities.
 - Interviewees suggested that such opportunities could usefully have focused on communication skills, analytical skills, business skills, personal development and background knowledge.
- Impact of participation on Service Users:

- Around half of Service Users enjoyed elements of participating in the NCSI and a few felt they had developed their skills as a result.
- A significant number of Service Users reported feeling frustrated, angry and upset about the experience.
- Chairs and Other Workstream Members mostly felt unable to comment on the impact of involvement on Service Users.
- Workstream Support Officers reported that Service Users' confidence increased through participating.

Conclusions & recommendations

Macmillan Cancer Support is committed to learning from the experience of Service User involvement in the NCSI.

Though that there are some examples of effective Service User engagement within the NCSI workstreams, the perceptions of those we interviewed suggest that Service User involvement in the NCSI has not achieved an adequate degree of impact and that involvement systems and processes across the different workstreams have been variable and inconsistent. User involvement in the NCSI has been patchy and ad hoc as a result of a lack of a vision for engagement driven from the top, communicated to everyone who leads workstream activities and stemming from a sense of a unifying approach to the work.

There has been little shared understanding about, or consistency in applying, a model for involvement, no clarity about the role of Service Users, and varying degrees of practical support provided. The combination of poor systems and processes, and a perceived lack of significant impact, has led many Service Users to express a high degree of frustration.

Moreover, there is a stark discrepancy between the assessment of Service Users and other workstream members. This applies both to their assessments of the extent to which Service Users' input was valued and supported, and to their assessments about the impact of Service Users' involvement. While most Service Users felt under-valued, sometimes marginalised, and prevented from making the level of impact they judged they could have made, the majority of Chairs, Workstream Support Officers and Other Workstream Members felt that Service Users had made a significant contribution and impact.

We can speculate as to the reasons for this discrepancy. It may be that Service Users themselves are in the best position to judge impact. It may be that Service Users made an impact which was not fully communicated to them. It may be that Service Users had higher expectations of the impact they could or should make, than did other workstream members, leading to lower satisfaction levels.

We have identified models of involvement that seemed to be operating within different workstreams (active strategic involvement, implementing and consultation). There has been a worrying degree of inconsistency in the models for, and approaches towards, involvement taken across different workstreams. Further, the involvement that has taken place seems to

have been at the 'lower' end (consultation). A lack of effective structures and support for Service User engagement can create a vicious circle. Service Users may feel undervalued and, as a result, cease participating fully. This would lead to them not having a major impact, which undermines the perceptions of other workstream members as to the value of Service User impact. This leads to Service Users not being integrated into an initiative at the higher end of our spectrum of Service User involvement.

In order to ensure effective Service User involvement in the future, we suggest that Macmillan Cancer Support consider producing written guidance for Service User involvement in future initiatives, to ensure there is shared understanding of the involvement model.

This guidance would address the key issues identified in this report, as follows:

- A vision for user involvement.
- Clarity of role. There are two types of consideration here, as follows:
 - The **function** of a person's involvement. Are Service Users intended solely to share their own experiences? Keep discussions 'patient-centred' by asking 'challenging questions'? Provide information or be a resource for the Service User experience based on the views of people in wider networks?
 - The **'level'** of input expected. To what degree are Service Users expected to input at a strategic or advisory level? Or are they expected to play a part in designing and delivering project/activity based initiatives?
- Capacity-building amongst non-Service Users, raising awareness and understanding of the benefits and processes of Service User engagement.
- Identification and recruitment of Service Users needs to be planned with Service Users so as to be transparent and provide choice.
- Communication. There need to be systems in place for communicating to Service Users, clearly and in a timely manner, decisions as to the future direction and structures of an initiative as well as the nature of practical support arrangements.
- Practical support. More needs to be done to provide adequate practical support for Service Users, to enable them to participate despite any logistical barriers.
- Learning and development for Service Users. This would begin with a clear induction process and include ongoing opportunities to reflect on their own learning.

- **Resourcing.** Macmillan Cancer Support might consider investigating what mechanisms and resources it can create to ensure that ideas generated by Service Users can be progressed.
- **Monitoring and performance management.** Adequate systems for monitoring and reporting on the process and outcomes of Service User engagement (to Service Users, and those responsible for overseeing their engagement) are needed to ensure that all participants have a shared understanding of the impact of Service User engagement.

1 INTRODUCTION

1.1 What is the NCSI?

Formally launched in September 2008¹, and running until 2012, the National Cancer Survivorship Initiative (NCSI) aims to improve services and support for those living with, and beyond, cancer, to ensure that survivors get the care and support they need to lead as healthy and active a life as possible, for as long as possible.

There are 1.63 million cancer survivors in England, and 2 million across the UK. This number is expected to grow by over three per cent per annum, in response to increasing incidences of cancer and better survival rates.

The NCSI, a key initiative of the Cancer Reform Strategy (2007), is being delivered by Macmillan Cancer Support in partnership with the Department of Health. It is co-chaired by the National Cancer Director, Professor Mike Richards, and the Chief Executive of Macmillan, Mr Ciaran Devane.

In February 2008, an event to identify survivorship issues was held with Service Users (a mixture of patients and carers), which was attended by 100 people. In March 2008, a second event was held with Professionals as well as Service Users and carers to consider how to address the issues identified by the first event.

In phase one, from September 2008 to April 2010, seven NCSI workstreams were established to identify user needs and develop new models of care, to meet survivors' needs within current financial and workforce constraints. Each workstream focused on either a stage in the 'survivorship pathway' or a cross cutting theme, and reported to a steering group. The workstreams and their Chairs were:

- Assessment and care planning: Ciaran Devane, Chief Executive, Macmillan Cancer Support;
- Managing active and advanced disease: Roger Wilson, Chief Executive, Sarcoma UK;
- Long-term consequences of cancer and its treatment: Dr Jane Maher, Chief Medical Officer, Macmillan & National Clinical Lead, NHS Improvement;
- Survivors of childhood and young people's cancers: Carole Easton former Chief Executive, CLIC Sargent Cancer Care for Children;
- Work and finance: Barbara Wilson, Co-Founder, Working with Cancer;
- Self-care and self-management: Professor Jessica Corner, Chief Clinician, Macmillan Cancer Support;
- Research: John Neate, Chief Executive, The Prostate Cancer Charity.

¹ Initial workshops were held with Service Users in February 2008, and with both professionals and users in March 2008.

The steering group and each of the above workstreams appointed two or three members who were Service Users (a mixture of patients and carers). In addition, some workstreams included health professionals who also had experience of using services. Macmillan Cancer Support or NHS Improvement assigned a Workstream Support Officer to each workstream to ensure the effective operation of the workstream, including good communications, processes, documentation and delivery.

The Service Users² involved in the initiative have had the opportunity to attend a quarterly Peer Support Group, facilitated by Macmillan Cancer Support. Macmillan Cancer Support created the Peer Support Group to provide a forum for Service Users to exchange information about what was happening in their workstream and share good practice in Service User involvement. It meets quarterly, facilitated by Macmillan Cancer Support and all Service Users are invited to attend. It is guided by Terms of Reference, which were produced by Macmillan Cancer Support with the input and approval of service users.

Much of the activity of the workstreams focused on researching and developing models of care. Some workstreams developed links with one or more of 39 test communities which tested models of survivorship care and support, supported by NHS Improvement. Twenty-nine test communities addressed care and support for adults and 10 tested models of care for children. Other workstreams tested supported self management pilots, consequences of treatment models, and models of vocational rehabilitation.

The workstreams were wound up at the end of phase one. In phase two (April 2010 to September 2012), the NCSI consists of 30 projects aiming to test the new models developed through phase one.

There are particular challenges involved in undertaking user involvement with people who have a serious illness. Sadly, two Service Users died during the course of the NCSI, with others needing to withdraw because of their health. A small number of Service Users were unable to participate in interviews for health reasons.

1.2 This evaluation

1.2.1 Objectives

Macmillan Cancer Support commissioned Papworth Research & Consultancy Ltd and InHealth Associates to evaluate user involvement in the NCSI. The aims of the evaluation were to investigate the following questions:

- What impact did user involvement have on NCSI workstream activity?
- What impact has user involvement had on the Service Users themselves?

² Throughout this document, when referring to 'Service Users' or 'Service User Representatives', we are talking about those Service Users who were specifically appointed as such amongst the workstreams (i.e. not those health professionals appointed who also had experiences of using services)

- What were the barriers and facilitators to effective engagement of Service Users in each workstream?

1.2.2 Method

Users were involved in the evaluation from the outset. The service users on the Peer Support Group worked with Macmillan Cancer Support to develop the tender, select the researchers and develop the model for the evaluation.

Papworth Research & Consultancy Ltd and *InHealth Associates* provided training to, and worked with, two Service User Co-Researchers³, Hugh Butcher and Alison Morton, drawn from the NCSI Peer Support Group. Papworth Research & Consultancy Ltd and *InHealth Associates* delivered a research methods training workshop with the Co-Researchers and facilitated a workshop to devise the evaluation methodology and the research tools (which were then approved by Macmillan Cancer Support and the Peer Support Group). The Co-Researchers undertook the fieldwork, supervised by Papworth Research & Consultancy Ltd and *InHealth Associates*. Papworth Research & Consultancy Ltd and *InHealth Associates* held an analysis workshop with the Co-Researchers before producing the first draft of the report, and inviting Co-Researchers to comment on it. Papworth Research & Consultancy Ltd and *InHealth Associates* incorporated the comments of the Co-Researchers before submitting the draft report to Macmillan Cancer Support and the Peer Support Group.

The evaluation methodology consisted of the following:

- A focus group attended by eight Service Users (all of whom also participated in one-to-one telephone consultations);
- 30 interviews as follows:
 - Telephone interviews with Service Users (all 22 Service Users were invited to participate, and 15 provided interviews);
 - Face-to-face interviews with each of the seven Workstream Chairs;
 - Telephone interviews with Workstream Support Officers (all seven were invited to participate and four provided interviews);
 - Telephone interviews with Other Workstream Members suggested by the Peer Support Group (nine were invited and four, across four workstreams, gave interviews). These were a mixture of healthcare professionals and representatives of third sector organisations, suggested by members of the Peer Support Group. In the remainder of this report, where the phrase ‘Other Workstream Members’ is capitalised, it refers to this group.

Collecting the views of the Department of Health, NHS Improvement and other organisations involved in the NCSI was outside the scope of this research and so this report does not necessarily reflect their views.

³ Initially four: one withdrew before the evaluation; another soon after fieldwork began.

The evaluation methodology collected data on the **perceptions** of interviewees (rather than objective truths). This enables Macmillan Cancer Support to understand the experience of interviewees and to identify learning as to how these experiences might be improved in future. Of course, it must be recognised that people's perceptions are always filtered through their previous experiences.

The evaluation methodology was qualitative. It is not appropriate to report qualitative findings in quantitative terms so, throughout this report, we indicate the extent of agreement among interviewees on key points by using terms such as 'few', 'many' and 'the majority' rather than stating specific numbers.

All verbatim quotes in the remainder of this document are drawn from the Service User focus group, which was audio-recorded. One-to-one interviews were not recorded so this report includes verbatim quotes only from Service Users. Where more than one quote is included within a section of this report, the quotes are drawn from separate Service Users.

The discussion guides used to structure these consultations can be found in Appendix One.

Papworth Research & Consultancy Ltd, InHealth Associates and Macmillan Cancer Support thank everyone who gave their time to this evaluation.

The remainder of this report is structured as follows:

- Section two outlines the models of user involvement developed by the seven workstreams;
- Section three presents the views of interviewees on the role of Service Users within the NCSI;
- Section four considers the impact Service User involvement has had on the NCSI;
- Section five discusses the factors interviewees felt facilitated effective user involvement (or could have facilitated it had they been present) and the factors they felt prevented it;
- Section six focuses on the skills needs that interviewees identified for Service Users;
- Section seven examines the impact of participation on Service Users;
- Section eight contains our conclusions and recommendations

2 MODELS OF SERVICE USER INVOLVEMENT

2.1 Research findings

Service User involvement was intended to be a central component of NCSI practice. One Chair told us that it was initially intended that Service Users would lead aspects of workstream activity and to chair, or at least co-chair, workstreams.

While several interviewees commented that Macmillan Cancer Support is committed to Service User engagement, they reported that workstreams were not guided as to how to involve Service Users and there was no single model of Service User involvement for the NCSI as a whole. Nor was a role specification created for Service Users. In addition, a few interviewees reported that the resources provided to support Service Users were not sufficient to enable Service Users to lead workstreams.

In this context, each workstream devised its own model of Service User involvement, some explicitly, others (as interviewees put it) “*by default*” which resulted in considerable variation between workstreams as to how user involvement was undertaken. We explore this further later in this report.

Around half of Service Users reported that their only involvement was through attending workstream meetings/teleconferences and Peer Support Group meetings. Others reported also being involved (to a lesser or greater extent) in the following activities:

- Activities directly related to the workstream:
 - Contributing to break-out discussions at workstream meetings;
 - Supporting the development of a partnership group linked to the workstream;
 - Working on a specific research project the need for which was identified by Service Users;
 - Involvement with test communities;
 - Participating in sub-groups/spin-off events;
 - Reviewing documents and preparing papers for discussion within the workstream;
 - Supporting other Service Users involved in workstream activities;
- Activities beyond the focus of the workstream:
 - Attending NCSI planning events, steering group and consultation conferences.

Comments from a few Chairs and Workstream Support Officers suggested that decisions as to how to involve Service Users were influenced by a commitment to take into account the impact on the Service Users themselves (see section 7). For example, one Chair suggested that full engagement in workstream meetings was the most challenging way to involve Service Users and demanded too much from users who might also be unwell. In addition, this Chair felt that this model was ‘*tired*’ - that co-design, co-creation and active involvement in projects provided more potential for real engagement with patients’ experiences and would have more of an impact. A Workstream Support Officer commented that much of the work of

their workstream was undertaken outside main meetings. This involved a significant commitment from professional members and it would not have been appropriate to involve Service Users in this as they were not paid for their time.

The evaluation data highlighted three models through which Service Users were involved in the workstreams (these were not mutually exclusive: workstreams involved Service Users in these ways to differing extents). They were as follows:

- Active strategic involvement: involvement in setting or shaping the strategic direction of the workstream and its priorities, or in co-design/creation of a project with other professionals;
- Implementing project work or the work of sub-groups, such as gathering data from other sources, setting up test community initiatives or co-authoring papers;
- Consultation: providing the Service User view to professionals to enable them to take it into account while setting or shaping the strategic direction of the workstream and its priorities or designing/creating a project.

We found some evidence that professionals would have welcomed a stronger steer on how to involve Service Users. For example, one Workstream Support Officer reported that a NCSI user involvement vision statement had been produced after the workstream had determined its priorities and developed its understanding both of the role of Service Users within the workstream, and of the role of the workstream within the NCSI. They suggested this seemed “*all a bit back to front*”.

2.2 Key issues

- Interviewees reported that workstreams were not guided as to how to involve Service Users, despite the fact that Service User involvement was intended to be a central component of the initiative.
- In the absence of a strong steer as to how to manage Service User engagement, workstreams each devised their own model of involvement, ranging from consultations, through implementation of project work, to active strategic involvement.

3 INTERVIEWEES' PERCEPTIONS OF THE SERVICE USER ROLE⁴

Many Service Users and Chairs reported that Service Users lacked clarity about their role.

"I thought I knew [what my role as a Service User was] until I did this project!"

*"I was very unclear of my role. I came with the view that I was there representing other Service Users within that workstream but it was not in line. There was no clarity as to what is going to be involved, what piece of work are we going to be really looking at, and are you able to make a contribution to that? And **how** do you make a contribution to that?"*

"I found it quite confusing. I would have liked, if I was doing it again, I would like to know exactly what they want from the three patient representatives that are there. What do they want us to do? Do they want us to do this or that or whatever? Be very clear about it, define it and understand how it's going to input to the rest of the work etc".

One Service User told us they had been frustrated in attempts to find out what their role was supposed to be, with enquiries about it simply being reflected back to Service Users:

"When I asked [the Chair, they] sent an email to the User Group to ask us to define our role within the group. I have constantly been asking what my role is and I still do not feel that I have had any clear definition of what my role in the group is...What we [the Service Users] define our roles to be is not the same as the role [other workstream participants] want us to play. The role on paper does not match up with the reality".

Through analysis of the data, it seems that perceptions as to the role that Service Users could, and should, play within the NCSI appeared to be influenced by the circumstances of the workstream (such as Service Users' and other workstream members' previous experience of Service User engagement) rather than reflecting any explicit strategy for, or approach to, engagement.

3.1 Service Users' perceptions of their role

Service Users did not distinguish clearly between **why** they were involved and **how** they were involved. The following are descriptions of the Service User role provided by several Service Users in each case:

- To draw on personal experience, bringing an informed patient perspective;

⁴ NB: Verbatim quotes are available only from the Service User focus group. The reader should take care not to overlook the views of Chairs, Workstream Support Officers and Other Workstream Members due to the lack of verbatim quotes from these groups.

- To draw on, or be a conduit for, a range of views through wider networks, such as user networks, voluntary activities, Cancer Voices, local hospitals, cancer peer reviews, and general networking. (However, one Service User argued that it was not feasible to *represent* patients/carers. Rather the role is to be a patient/carer *advocate*);

“I do a wide range of things and I represent lots of different people with cancer...that has to be it. There is no point in being [just] a Service User...The idea is that I’m a proactive Service User engaging right across the board and...it’s my role to make [the workstream] aware [of issues it might be missing]”.

- To keep their workstream on track, i.e. focused on improving services for Service Users and dealing with what is of most concern and benefit to patients and carers, rather than going off agenda into high-flown/academic discussion. *“Don’t forget the patients”.*
- To create a two-way flow of information:

“To facilitate the voice of the patient/carer and general public for the organisations that I sit on...I would ask questions and gather information to feed back to other groups”.

“I take that back into my local network, where I’m also on the tumour group and the research panel. And it feeds both ways and I can achieve change in practice locally and at national level as a patient”.

“I think that conduit that you talked of there is such an important step to user involvement. There’s a two-way channel of information”.

The following are views which were each expressed by just one Service User:

- To ensure a holistic focus (e.g. including a focus on support beyond immediate medical needs);
- To make Service Users central to the workstream;
- To ensure Service Users views are included in decision-making;
- To challenge thinking, perceptions and comments;
- To provide ‘weight’ and legitimacy to the activities of the workstreams;
- To advocate for the improvement of services for cancer patients;
- To ensure that the NCSI results in survivorship services being responsive to individuals’ personal needs, rather than consisting of *“tick-box, top-down, blueprint programmes”.*

Thus the perception of the majority of Service Users as to Macmillan Cancer Support’s motivation for involving them reflected Macmillan Cancer Support’s intentions. In contrast, however, a couple of Service Users were sceptical about motivations for Service User involvement. One suggested that, while Service Users were involved to comply with NICE

Improvement Outcome Guidelines, the motivation for this was solely in order to improve the chance of securing funding. Another suggested that senior clinicians and academics insisting that Service Users are involved in all developmental activities relating to cancer, wasn't enough to ensure that Service Users were involved appropriately or effectively. As a result *"they try to find tokenistic jobs for us that have very little meaning"*.

3.2 Other Workstream Members' perceptions of the role

Other Workstream Members reported valuing the input of Service Users, defining the Service User role as:

- To bring knowledge based on personal experience (e.g. providing insights into where gaps exist in service provision, drawing on experience of the full care pathway). One Chair explained that, while healthcare professionals sometimes find it frustrating to hear Service Users' personal stories (feeling that relating such stories is a waste of time because they are not generalisable), such stories can open up new lines of thought;
- To bring knowledge drawn from their wider networks;
- To take information and proposals out to wider networks;
- To provide legitimacy and credibility to the outcomes of the workstream;
- To challenge and *"ask the awkward question"*;
- To keep the workstream appropriately focused, for example:
 - 'Grounded in reality' (i.e. using their personal experiences as a reality, a check for the ideas generated from a theoretical perspective by health professionals);
 - Focused on its stated outcomes (whereas health professionals are more likely to be distracted by interesting side issues);
 - To maintain a holistic approach (whereas health professionals are more likely to become overly focused on a particular feature of a patients' condition, lifestyle or treatment);
 - Mindful of the end user of the services it is developing, i.e. patient-centred.

One Chair (who suggested that the impact of Service Users on their workstream was 'low to moderate') described the engagement of Service Users in their workstream as *'reactive'*: picking up on issues and concerns as they surfaced rather than driving the agenda of the workstream.

3.3 Service Users' perceptions of the understanding that other workstream members have of their role

A minority of Service Users felt unable to comment on what other workstream members thought their role was about as it had never been discussed. However, most suggested that all workstream members would agree that the Service User role was to draw on their existing understanding of the needs and views of people affected by cancer. Others suggested that workstream members thought the Service User role was about:

- Highlighting the user perspective;

- Bringing knowledge and experience;
- Focusing on quality of life and medical care standards.

Several Service Users felt that health professionals failed to recognise the value of Service User involvement.

“Professionals...don’t always understand what the patients and carers, the people affected by cancer want from this, what expertise they do bring from it and in a way they automatically just tick-box us”.

One Service User reported that workstream members tended to dismiss their input as anecdotal.

A more widely reported issue was that Service Users felt that professionals assume that Service Users are speaking only from personal experience. Service Users reported that professionals seem to underestimate the extent to which Service Users can draw on experience from other networks, possibly even being unaware that Service Users **had** this wider experience:

“I represent a lot of other people. Professionals within the workstream they came with a single expertise. So, just like they were representing themselves, they thought I was only representing me. I was not and I think that is the breakdown in communication”.

“I think one of the first things that needs to be done is to determine whether we’re there as individuals...or delegates. The two are quite different”.

This Service User perception was supported by quantitative data we collected within the interviews which suggested that there was a discrepancy between the views of Service Users and Chairs as to what Service Users’ roles **should** be, as follows:

- On average, Service Users agreed marginally more strongly than did Chairs with the statement “Service Users should draw on their existing understanding of the needs and views of people affected by cancer related to my workstream”;
- On average, Services Users agreed more strongly than did Chairs with the statement “Services Users should act as a link between the NCSI and relevant people affected by cancer”;
- On average, Chairs agreed much more strongly than did Services Users with the statement “Services Users should provide input to the NCSI based on their own views and needs”.

3.4 Key issues

- Service Users and Chairs both felt that Service Users lacked clarity as to their role.

- Given this lack of clarity, the role of Service Users seemed to have been determined by the circumstances of each workstream (such as the type of work it was doing, and the experience of other members of Service User engagement or of using services themselves).
- Service users played a variety of different roles across workstreams to ensure work was 'patient-centred': from keeping workstreams focused on the 'holistic needs' of patients through to drawing on others' experiences.
- Several Service Users felt under-valued, particularly with regard to their ability to draw on wider networks as well as report their own experience.

4 IMPACT OF SERVICE USER INVOLVEMENT ON THE NCSI

In this section, we consider whether Service Users were ‘heard’ within their workstreams (i.e. did others’ listen to, understand, and take into account, what they said), the impact they had on the process of the workstream (the ways in which it worked and its efficiency) and the impact they had on the outputs of the workstream (the results achieved).

4.1 Were Service Users ‘heard’?

Service Users were roughly equally divided between those who felt ‘heard’ (though with caveats, for example as to whether their input had had an impact) and those who either didn’t know whether they were, or felt sure they were not.

“I was heard to some extent, but not fully”.

“I hope so, but we won’t know until the next NCSI conference because the workstreams have now been disbanded. Let’s see how the test projects go and how user-friendly they are”.

“We’ve tried to put our point of view but I feel that it’s always been sidelined, I just don’t think that it’s been properly listened to”.

“I have done nothing and I wonder why they waste so much money on our train fare. If it carries on as it is, I will have zero impact as I just attend meetings and I don’t know why am there...If it carries on as is, I am not sure that I can carry on with this workstream”.

Chairs and Other Workstream Members generally felt that Service Users were ‘heard’ within their workstream with the issues addressed often being determined by what Service Users’ said were important. They pointed to the following, as evidence of this:

- Service Users contributions led to shifts in thinking which were reflected back by healthcare professionals in later meetings.
- Service Users’ comments stimulated substantial quantities of other significant comments from other workstream members.
- Workstreams addressed issues identified by Service Users as important (though the degree to which this happened varied. In one workstream, the Chair reported that the priorities of their workstream were entirely driven by Service Users. Within another, the Workstream Support Officer described Service Users as ‘*middling to bottom*’ in influence by comparison with other workstream members: contributing to, rather than setting, the agenda).
- The contribution of Service Users tended to broaden the scope of the workstream. Services users wanted to “*take on anything and everything*” and “*change the world*” as opposed to other members who were concerned to stay focused and realistic.

4.2 What impact did Service User involvement have on outcomes?

There was no formal measurement of the impact of Service Users on the NCSI, or guidance provided to individual workstreams regarding the measurement of impact. However, within at least one workstream, Service Users met with the Workstream Support Officer regularly to review how much they were achieving.

Within this evaluation, Chairs agreed more strongly with the following statements than did Service Users:

- In this workstream, Service Users were prime movers shaping aspects of what is being achieved.
- In this workstream, Service Users supported sub-groups of workstream members to shape aspects of what was achieved.
- In this workstream, Service Users helped workstream members to understand user perspectives on specific aspects of what was achieved.
- In this workstream, Service Users raised workstream members' awareness that there is a user perspective on specific aspects of what was achieved.

In line with this, Service Users agreed more strongly with the following statement than did Chairs:

- In this workstream, Service Users made no discernable impact on what was achieved.

The views of Workstream Support Officers and Other Workstream Members tended to fall between the two.

Service Users were roughly equally divided between those who felt they probably had had an impact on the NCSI, though they were far from certain, and those who either didn't know whether they had or felt sure they had not.

"I would like to think that I have raised awareness with certain people through Macmillan about certain issues. Now whether this actually in the end is distilled into something is quite different".

"I had no effect, no impact at all...I don't think most of them even knew who I was".

No Service Users felt able to say beyond doubt that they had made a significant impact and only one Service User was able to point to any evidence of impact (their words and ideas used in the development of a model).

“Nothing has come out of it...What work I’d done...showed that there is a need...Now if there is evidence to show that there is a lack of service, why is that not heard? Why is that not picked up?”

“The thing is you can have a voice but whether or not that voice is heard is another question. So I would say I definitely have been on and on...but I don’t know whether or not it’s been heard”.

Several told us they would have welcomed the introduction of a system with the NCSI to provide them with formal feedback on the contribution they were making and the impact they were having.

A lack of evidence that they were having an impact led many to conclude that their involvement had been tokenistic.

“They’re going to be able to sign the box that says they have user involvement. And actually it’s not actual real user involvement”.

“We’re just tokens aren’t we, really?”

“It’s a waste of our time as we do so little. I do not think we add value and this is reflected in the fact that we do not get any remuneration for our time”.

A few explained that this was exacerbated by a sense that they were allocated at random to workstream activities or subgroups without having a say as to which activities they undertook:

“We were put into subgroups but we were never asked ‘Do you think these subgroups are relevant to what we’re doing?’ We were just told ‘There’s the three subgroups. You can go on any of them basically’. They hadn’t said ‘You’d be more appropriate for this one or this one. You just sort of picked one’”.

“So surely you have to ask the question as to how important we actually are if they can just pluck names and put you there, there, there and there”.

Those that thought they **might** have had an impact (though, as already stated, none were sure they had) suggested their involvement had resulted in the following:

- An increased focus of the workstream on specific issues (e.g. how people whose cancer recurs can quickly get back into the system, the challenges the benefits system poses to Service Users);
- The creation of a holistic culture and thinking, taking into account the full range of support required by cancer survivors (for example, including the psychological impact of

cancer at all stages of the pathway, not just post-treatment) and the full Service User experience;

- Health professionals on the workstream being more aware of the information resource that Service Users provide;
- Greater confidence of workstream members in statistical findings that Service Users could confirm from personal experience.

A minority of Workstream Chairs and Other Workstream Members felt able to report significant outcomes as a result of Service User involvement, with these few reporting the following:

- Increased take-up of pilot provision developed through the workstream, as a result of the credibility provided by Service User involvement in its development;
- Ensuring documents developed for patients were user-friendly;
- Determining the data to be collected about patients;
- Influencing the design of a pilot approach;
- Identifying a need for a specific project;
- Work being undertaken jointly between Service Users and professionals.

4.3 Key issues

- Service Users were roughly equally divided as to whether or not they felt ‘heard’, though those that did feel ‘heard’ were unsure whether their input had made a difference.
- Service Users at best thought that, although they had been listened to, their views had little impact and, at worst, thought they had not been heard.
- Chairs and workstream members reported that Service Users had had an impact on the workstreams’ activities. However, this varied across workstreams.
- A few examples of the impact of Service User involvement were highlighted in some workstreams. These were defined in a variety of ways including the ‘atmosphere’ of involvement (e.g. increased trust and better relationships), improvements in the process through which issues were taken forward (e.g. a pilot approach being developed differently) and issues that users worked on specifically (e.g. patient information).
- There seemed a striking difference in views between Service Users and other workstream members about whether users had been listened to and/or had had an impact.

5 BARRIERS AND FACILITATORS TO EFFECTIVE SERVICE USER ENGAGEMENT

There was considerable variation in the extent to which Service Users felt supported to be effectively involved. Below we consider factors that hinder and facilitate effective involvement based on the following:

- Factors that Services Users told us created barriers by their absence;
- Factors that Service Users told us **would have** supported them had they been present;
- Factors that Service Users told us supported them to engage effectively.

5.1 Underlying attitudes to Service User involvement

5.1.1 Perceptions of Service User involvement held by other workstream members

As reported in section 3, a majority of Service Users felt that members of their workstream failed to recognise the potential value of Service User engagement, or of the ability of Service Users to provide input based on their wider networks (rather than just their own experience).

“They did not want to focus on the patients; they wanted to lead on the professionals to carry out bits of work that they were interested in...We had a valid position due to our vast experience...This was a missed opportunity. They are now having to use focus groups, when we could have approached the cancer networks, support groups, but they put out bids so that they could employ more professionals...Macmillan have become complacent with what they have via patient/carer expertise”.

According to one Service User, this even led to ideas generated by Service Users being taken forward, and credited to, professionals:

“They take our ideas from us and take all the credit. [Service Users] can never be the lead or the driver as far as Macmillan is concerned”.

5.1.2 Feeling marginalised

Several Service Users were frustrated by their perception that their workstream was driven by a Macmillan Cancer Support agenda or the Chair’s agenda. They reported, for example, that this led to a project on which they were working being ‘sidelined’, leaving them feeling that the project had been given to them in a tokenistic way:

“Particularly with [a specific topic] that came to our workstream, that had already been decided by Macmillan, it was presented to us as a fait accompli. There were all sorts of issues that we weren’t as users particularly concerned about but no one was listening...We did not have as much input as I would

have liked...The money was already spent and little left for the user-led ideas”.

“I worked [on a specific project]...did a lot of work, and then suddenly nothing happened. And I said to...the Macmillan representative there ‘What happened?’ and he said ‘Ah, there’s a budget decision. We haven’t got any funding for [the policy area] so, until somebody decides if they’re going to give us any more money, we can’t do any more with that bit’...There was also another...piece of work...suddenly it’s dropped because they’ve got x things they’ve got to achieve by a certain date...I spent a lot of time on that”.

“It becomes tokenistic because, at the start of an involvement, we go through an exploratory session of what should happen but what we don’t get told is: there is already a set agenda...And I think that’s how it becomes tokenistic because why ask if you’re not going to take it on? And I think that’s the frustrating thing”.

“There was a piece of research presented in the first meeting that we had and everything thereafter was predicated by that piece of research...It was obvious that that was the path that they were going down”.

5.2 Systems and processes

5.2.1 Clarity of role

The strongest theme within the data around facilitators and barriers to effective Service User engagement concerns the need to ensure clarity of role for Service Users. All stakeholders (Service Users, Chairs, Workstream Support Officers, Other Workstream Members) reported that there was a lack of clarity of Service User role during the NCSI work. See section 3 for further data relating to this.

5.2.2 Effective meeting facilitation/chairing

The factor cited most frequently by Service Users as enabling effective Service User engagement was skilful facilitation or chairing. Service Users regarded the following as elements of effective facilitation/chairing:

- Introducing each member of the group at the start of a discussion;
- Beginning meetings with a summary of previous discussions/actions;
- Meetings being structured in such a way as to encourage Service User input (e.g. making Service User input an agenda item⁵, making space for Service Users to tell their personal stories, break-out groups, enabling Service Users to contribute to agenda-setting);

⁵ Although one Chair explicitly expressed the view that Service User involvement should **not** be a separate agenda item as this could lead to it being marginalised. Rather, it should be integrated throughout discussions.

- Using new technology such as online discussions (this was also suggested by a Chair);
- Explaining technical language and/or preventing members from using technical language:

“User involvement has been around for a very long time...We all speak the same language. It is about time health professionals did actually accept that we can talk one language without a higher one, there is that middle level, and I’m sorry they should have been able to do that. It’s not difficult”.

- Holding initial discussions to develop an understanding of members’ styles of communication and what each might contribute, and agree terms of reference such as how meetings would be conducted.

Chairs reported that the actions they took to enable Service Users to participate effectively included the following:

- Having an agenda item for Service Users;
- Inviting/encouraging Service Users to ask constructive questions;
- Inviting/encouraging Service Users to suggest agenda items;
- Encouraging Service Users to ask for clarification of anything they don’t understand.

A few Service Users reported that their meetings **had** been effectively chaired, with the Chair using a ‘facilitative’ style to ensure that Service Users were brought into discussions if such discussions were being dominated by others.

“On the teleconferences that I was part of...it all went round and suddenly I’d get...the Chair saying ‘Hang on a minute, what does [name] think about that?’ And so actually on the teleconferences I felt a little bit more included than perhaps at the meetings”.

Workstream Chairs who were themselves Service Users saw themselves as at least partly responsible for supporting Service Users and ensuring they were able to engage effectively. This was reflected in the experience of Service Users within their workstreams, who reported that their Chair had effectively included them in discussions;

“Our Chair is actually a patient and I suspect that’s made a difference...I’ve actually brought it up with [the Chair] afterwards and said ‘This isn’t for me because you know we’re not being heard’ and so he has said ‘Listen, at every other meeting as soon as it starts to get really technical call them back’, so I have done and... they listen and actually ask us”.

“Because he was a patient he understood where we were coming from and...sometimes it got too involved on the medical side and we just couldn’t understand...and he’d stop them and say “listen you need to really explain that, [the Service Users] don’t understand what you’re on about.” ...He just

sort of asked us at the end of every meeting, is there anything we needed to bring [up]?”

The data suggests that, when other workstream members (the Chair and/or healthcare professionals) were Service Users themselves this provided critical mass for Service Users, gave Service Users credibility, and provided Service Users with role models.

However, the majority of Service Users felt that the way their workstream meetings were chaired could have been improved.

“I had said that I would be a little bit late...and I got there about 20 minutes or so into the meeting and there wasn't even a break to say ‘This is [name], come and join us, glad you could make it’ or anything. I just found a place and I sat there...And I came away and I thought ‘Well that was a waste of time’”.

“I've spent two hours on telephone conferences without being brought into the conversation”.

One Service User's experience went further than being excluded by omission, in that they had experienced their views being dismissed.

If I wanted to say something, somebody would say ‘Oh no, we know what you think’. And I was actually shut up...Mainly the Chair actually”.

5.2.3 Sharing biographies

As part of the set-up process, Service Users would have welcomed an opportunity to share their own biography and learn about those of other workstream members. Service Users reported that other workstream members were told little about them, or their relevant knowledge and experience, and that this led to their input being undervalued.

“My first meeting, I wasn't even introduced”.

“For that group to understand me they need to have some background on me...I actually had to provide a personal profile with a lot of other groups [outside the NCSI] I engage with”.

“I'm sure the Chairs could have met with us, the Service Users, for like even half an hour just to find out our background and everything”.

5.2.4 Transparency of recruitment procedures

A number of Service Users were selected to participate in specific workstreams due to their prior involvement in activity relating to the topic of the workstream, or to their interest in or experience of the issues relating to the topic. The limitations of this approach are that it's not

transparent, and it can prevent other Service Users getting involved and bringing a fresh perspective. It may also raise unrealistic expectations based on the extent of Service Users' previous involvement and impact.

Most Service Users were unaware of the reasoning behind their allocation to a specific workstream. They were under the impression that it was not related to their specific knowledge or experience and felt that this disadvantaged them within workstream discussions.

"We were just selected and told we were on this or that group".

"I left because I didn't feel that I was necessarily appropriate for that group. The second group...I still don't feel when I go to meetings or I'm on the end of a phone that actually I'm relevant".

A few Service Users felt that the focus of their workstream was such that it didn't require Service User input as it didn't focus on something on which a Service User would have a unique perspective.

Service Users would have liked to select which workstream to join (possibly after a trial period with more than one) or at least be told why they were selected for a workstream. Where Service Users happened to be on workstreams about which they had strong views and relevant experience to share, both Service Users and other workstream members felt this assisted them to make an impact.

A few Service Users were frustrated that additional Service Users were recruited, on an ad hoc, basis by other workstream members, feeling it lacked transparency.

5.2.5 Induction

Service Users would have welcomed a formal induction to introduce them to the NCSI, clarify their role, and provide them with relevant knowledge and understanding. One Service User told us their experience was *"in at the deep end and off we go"*.

The impact of not being formally inducted was compounded for Service Users who joined workstreams once the work was already underway.

5.2.6 Communication

Many Service Users felt that they had not been adequately informed around the changes to the NCSI as phase one came to an end (see section 1.1). They found this frustrating and alienating and it left them with a sense that their contribution was under-valued.

Others reported that they had not received emails and other communications circulated by their workstream.

5.2.7 Working in sub-groups and/or on specific projects

Where Service Users had worked on specific projects within their workstreams, they found the experience rewarding. Similarly, both Service Users and other workstream members reported that Service Users had been able to contribute more effectively when workstream meetings broke into smaller groups for discussions. This may, however, be as much a reflection of the extent to which Service Users felt **unable** to contribute to full workstream meetings, as it is a reflection of the effectiveness of this way of working.

A Workstream Support Officer suggested that, rather than have Service Users comment on draft documents generated by others, asking them to generate the first draft of materials would have been a more effective way of engaging them. The latter put Service Users in a position of challenging and arguing rather than creating and developing.

5.3 Support

5.3.1 Peer Support Group

Several Service Users and Chairs reported that the purpose of the Peer Support Group wasn't clear to them and suggested that it didn't live up to its name (by providing peer support). For example, a Workstream Support Officer reported that Peer Support Group meetings were not effectively 'distilling and connecting' experiences and that there was no reliable central infrastructure for administration (e.g. expenses). This interviewee suggested that Peer Support Group meetings should have been used both to ensure that Service Users understood the work of all the workstreams, and to resolve practical issues.

One Chair reported that, because they had assumed that the Peer Support Group **would** enable Service Users to resolve concerns, they didn't create a structure for this within their workstream. Although Macmillan Cancer Support reports that all Service Users were invited to participate in the Peer Support Group, at least two Service Users and one Workstream Support Officer were unaware of the existence of the Peer Support Group⁶ stating in interviews that there needed to be a structure to encourage/enable Service Users to communicate with each other across workstreams.

One Service User said that Peer Support Group meetings would have been more useful if they had included opportunities to have discussions with other Service Users, without Macmillan Cancer Support staff being present⁷.

⁶ Though it may be that they didn't recognise the title 'Peer Support Group' and so reported in consultations that they were unaware of the group whereas in fact they knew it by another name.

⁷ Macmillan Cancer Support reports that this was tried unsuccessfully. Attendance at unfacilitated meetings was poor and some Service Users reported that other Service Users dominated unfacilitated meetings with discussions of irrelevant topics.

5.3.2 Specific responsibility for Service User support

Where a workstream had individuals with specific responsibility for Service Users, their role was to recruit Service Users (identifying them through Macmillan Cancer Voices, communicating them about their interests and whether the workstream was appropriate for them), introduce them to the focus and overall aims of the workstream, check with them periodically to see if they were comfortable with proceedings, and work intensively to support them on specific pieces of work.

However, the data indicates that, within most workstreams, no-one was explicitly allocated responsibility for Service User engagement. The role usually fell by default to the Workstream Support Officer, sometimes jointly with the Chair or another workstream member. A few Workstream Chairs reported that it was difficult for them to support Service Users adequately because they didn't have the time or resources to make contact with Service Users outside workstream meetings. One felt that this would have been inappropriate as the approach within the NCSI was **not** to treat Service Users differently.

On other workstreams, the Chair and Workstream Support Officer supported Service Users through actions such as the following:

- Assisting Service Users to identify the activities with which they'd like to be involved;
- Meeting with Service Users before each meeting;
- Encouraging Service Users to have dialogue amongst themselves;
- Listening to, and acting on, input from Service Users;
- Encouraging Service Users to use resources available, e.g. admin support and access to remuneration;
- Ensuring that travel needs were met;
- Ensuring Service Users were brought up to speed if they missed a meeting.

Where workstreams **didn't** have someone in a Service User support role, Service Users reported that they would have welcomed a named individual to contact if they were unsure or concerned about something, and for this person proactively to check in with them between meetings. One suggested this could have been achieved through an explicit link between Service Users and Macmillan Cancer Support's Inclusion Team.

5.3.3 Resources

A few Service Users suggested that work undertaken by Service Users was inadequately resourced.

"We were excluded from carrying out our practical ideas. This was in contrast to the tenders put out to the professionals...When it came to what I was interested [in] which might have required support and financial backing, I could not take this any further as there was no resources for us...We were excluded. We had this great opportunity and it never happened...We had

nothing to do and we could have pooled our skills but they did not need us and that was obvious”.

“They said ‘Go for it’, but nobody’s told us about the time span, nobody’s given us enough resource...In the early stages you need face-to-face to pull things together and then you can do teleconferences, so nobody said how much funding there is for us to be able to do that, how frequently we can do it, who is involved, what is the time span. All that as part of resourcing information that you require for something to take off so it can be done systematically, so it looks professional. It is very difficult to put together a letter and then put your signature at the bottom and you think, ‘I’m not really happy with this but my name is at the bottom’. Because it makes you look very unprofessional”.

5.3.4 Learning & development

Both Service Users and other workstream members suggested that Service User impact would have been facilitated by the provision of more learning and development opportunities for Service Users. One Chair explained that, while they were committed to developing a Service User involvement model involving co-design and co-creation of project activities, such a model would have required the involvement of better supported and equipped Service Users. Further detail on this is provided in section 6.

5.3.5 Practical support

Several suggestions were made for ways to strengthen practical support, including the following:

- Prompt and trouble-free reimbursement of travel costs;
- Provision of documents in hard copy as well as electronic format;
- Accepting input through a variety of formats (e.g. including email) which enabled Service Users to contribute when they were unable to attend meetings. A few Service Users had struggled to attend workstream meetings because they lived a long way from where meetings were held while, as one interviewee put it: *“you have to be fairly healthy to contribute to NCSI”.*

Other practical initiatives which Service Users suggested would have facilitated user involvement included the provision of a glossary of terms (a *“jargon-buster”*).

5.4 Key issues

- Several Service Users felt that they had been marginalised during this programme of work and that their value had not been recognized.

- Creating clarity around the role of Service Users, and a shared understanding of this, would have improved both the experience of Service Users and their perception of any impact they had.
- The way in which meetings were chaired was seen by Service Users as key to their experience and the extent to which they were heard. Most felt that the way meetings were chaired could have been improved, although a few reported that meetings **had** been effectively chaired, and Chairs reported ways in which they had sought to facilitate Service User engagement.
- It is clear that greater transparency of the procedures by which Service Users were allocated to workstreams would have improved Service Users' experiences. They would have welcomed a formal induction process, and sharing biographies could have formed part of such a process.
- There is evidence of communication breakdowns, with Services Users reporting that the changes as the NCSI moved into its second phase were not adequately explained to them and that some inter-workstream communications didn't reach them.
- It appears that the structures for supporting Service Users were not always as effective as they might have been. Interviewees of all types reported lack of clarity over the role of the Peer Support Group, and lack of clarity over whose role it was to support Service Users
- Some Service Users reported a lack of resourcing for their activities, learning & development opportunities and practical support.

6 SKILLS NEEDS

6.1 Research findings

Interviewees were asked what skills Service Users required to participate effectively in the NCSI and whether they needed training in these areas. Interviewees tended to conflate the answers to these questions, which are shown in Table 6.1. Although a few Service Users felt they didn't need skills development, most Service Users and other workstream members felt that Service User impact would have been improved had Service Users been provided with learning and development opportunities focusing on communication skills, analytical skills, business skills, personal development and background knowledge.

Table 6.1: Service Users' learning & development needs

Learning/development	Identified by Service Users	Identified by other workstream members
Communication skills		
Giving presentations	✓	✓
Discussing/debating	✓	
Asking for clarification/challenging confidently	✓	✓
Listening	✓	✓
General communication skills		✓
Analytical skills		
Analysing written material	✓	
Deciding which issues to prioritise	✓	✓
Business skills		
Participating in/chairing a meeting (e.g. agendas, when to speak, AOB)	✓	✓
Project planning	✓	
Networking skills		✓
ICT skills		✓
Personal development		
Assertiveness/influencing	✓	✓
Not taking disagreement or rejection of one's ideas personally	✓	
The ability to see beyond one's personal experience	✓	✓
Background knowledge		
Understanding of healthcare structures		✓

6.2 Key issues

- Most Service Users and other workstream members felt that Service User impact would have been improved had Service Users been provided with further learning and development opportunities.
- Interviewees suggested that such opportunities could usefully have focused on communication skills, analytical skills, business skills, personal development and background knowledge.

7 IMPACT OF PARTICIPATION ON SERVICE USERS

7.1 Views of Service Users

Around half the Service Users had enjoyed elements of their participation, saying that they felt privileged to be involved, that it had increased their respect for the NHS and that it had widened their knowledge and networks.

“I’m proud of what I’ve learned....It’s been great learning curve, and...this is something that...would look good on a CV anyway that you’ve been involved in it. It’s helped to build my confidence...It’s helped a lot personally”.

“I have met a huge number of very interesting people from very different walks of life, and I’ve found that a very positive experience. And I also find that...it’s one of the things that helps keep the grey matter going”.

A few Service Users reported that, through participating in the NCSI, they had developed their skills in speaking and presenting to groups (including being able to argue their point of view and present questions effectively), analysing data and managing people.

However, despite this, a significant number felt frustrated and/or angry about their experience. They described having low morale and feeling fatigued as a result of confusion about their involvement and a sense that their contribution wasn’t important or effective. One was upset by the way their involvement had been ‘terminated’ (when the workstreams were wound up), finding it blunt and reporting that they had not been thanked. A few had ceased to be involved in the NCSI as a result of their experience.

“That is why I left. It was not enough to be part of something; I had to be doing something....I had something to contribute...I have had cancer...I no longer felt that my expertise was recognised”.

One said they would not work with Macmillan Cancer Support in the future. One reported that the experience had knocked their confidence and led to them questioning the value of user involvement altogether.

“It’s made me feel like a nuisance for asking why I am there! I did not feel that I could voice my opinions. I do not know if I should speak out about how this has knocked my confidence or just bow out quietly”.

Another said they would be wary of taking on such a role in the future.

“I have many calls on my time, where I know that I can make a difference, and where I feel my input is genuinely valued”.

7.2 Views of Chairs

Most Chairs felt it would inappropriate for them to speculate as to the impact of involvement on Service Users. However, one was prepared to say that they felt that it had been mostly positive, citing an example of a Service User who had been empowered by sharing experiences in workstream meetings. The Chair suggested participation had increased this Service User's sense of self-worth and value, boosted their confidence and confirmed to them that they could, and was, making a difference that would benefit others. It left them feeling there had been some point to their cancer journey.

7.3 Views of Workstream Support Officers

Workstream Support Officers reported that Service Users' confidence increased, as evidenced by them speaking out more and, for example, taking on the role of facilitator at a workshop. However, one also suggested that involving them in discussions when they are unsure of the contribution they can make can have a negative impact on them. As can discussions about sensitive issues, such as death and dying. They stressed the importance of providing personal support around such eventualities. However, Service Users did not express a demand for such sensitivity or support.

7.4 Views of Other Workstream Members

Other Workstream Members mostly felt unable to comment on the impact of involvement on Service Users. However, one commented that Service Users had learned about how the NHS operates and the complexity of what is involved, and were left reassured that future developments would reflect Service Users' needs. At the same time, this consultee suggested that change would be slow.

7.5 Key issues

- Around half of Service Users enjoyed elements of participating in the NCSI and a few felt they had developed their skills as a result.
- A significant number of Service Users reported feeling frustrated, angry and upset about the experience.
- Chairs and Other Workstream Members mostly felt unable to comment on the impact of involvement on Service Users.
- Workstream Support Officers reported that Service Users' confidence increased through participating.

8 CONCLUSIONS & RECOMMENDATIONS

Macmillan Cancer Support is committed to learning from the experience of Service User involvement in the NCSI. In our experience, developing a successful approach to Service User involvement is dependent on many things: and it is not easy. It requires a high degree of senior level commitment and ownership, a coherent approach (or ‘model’) to underpin the work, consistent systems and processes, a culture that values Service User contribution, and support (practical, resources, learning) for both professionals and users to work well together.

There are perennial issues and stumbling blocks. For example, lack of clarity about purpose (of an initiative, of a workstream, of individuals’ roles) are common to many endeavours, and if you don’t get these things right at the start, the consequences are easy to foresee. Certainly, the NCSI has suffered from a lack of clarity about the purpose of involvement at several levels: and it is not alone in this respect.

The perceptions of those we interviewed suggest that Service User involvement in the NCSI has not achieved an adequate degree of impact. While this evaluation was not designed to be an objective audit of impact, the high degree of negative perceptions is not encouraging. While lack of demonstrable impact and outcomes is again not unusual, our work with other Service User involvement initiative usually reveals more positive perceptions.

It is encouraging though that there are some examples of effective Service User engagement within the NCSI workstreams, particularly where Service Users have been influential and/or involved in specific activities or projects associated within the workstreams. There are also instances where Service Users have helped to shape the work of the workstream itself or helped to keep the workstream ‘on track’ or patient-focused. These good examples seem often to be attributable to the leadership qualities of individual Chairs (able to support effective ways of working or provide user-centred facilitative skills), or to the particular qualities of individuals who found themselves to be in a conducive environment. There is obviously much to build on: and the good work and the goodwill need to be harnessed.

In fact, it is the **variability** and **inconsistency** of involvement systems and processes across the different workstreams that are the hallmark of this study.

Our experience in the user involvement field suggests that successful initiatives are often dependent on ‘champions’ of the work. Formalising systems and processes is not straightforward. Variation is to be expected, to some degree. However, for a large scale involvement venture such as this to succeed, a vision for engagement needs to be driven from the top, be communicated to everyone who leads workstream activities and, vitally, needs to stem from some sense of a unifying approach to the work. It is clear that this sort of coherent approach was lacking.

Without understanding or appreciating fully the context within which the programme was developed, it is hard to know why this was the case. This is something that the NCSI and

Macmillan Cancer Support need to reflect upon. As a result though, Service User involvement within the NCSI workstreams has been patchy and ad hoc, with Service Users divided as to whether user involvement has had an impact (on processes, outcomes or their own satisfaction), and few sure that it had. Success seems more than usually dependent on circumstances (e.g. a Chair who happens to have Service User experience, the level of experience of a Service User, the relevance of a Service User's experience to their workstream).

Overall, then, the scale of this involvement endeavour coupled with poor systems and processes seems to have been a major barrier to success. The evident passion and commitment from many individuals (within Macmillan Cancer Support, within the workstreams, from some high quality Chairs and many Service Users) was not enough to ensure success.

The sense of uneven implementation of Service User involvement is deepened when one analyses the systems and processes of involvement. There has been little shared understanding about, or consistency in applying, a model for involvement, no clarity about the role of Service Users, and varying degrees of practical support provided. The combination of poor systems and processes, and a perceived lack of significant impact, has led many Service Users to express a high degree of frustration. The strength of this frustration is a striking hallmark of this study.

In our experience of service user engagement elsewhere, service users generally recognise an organisation's motivations for involving Service Users as arising from a recognition of the knowledge they bring and contribution they can make. It is therefore surprising that, within the NCSI, there were a small number of Service Users who believed that they had been brought in solely to improve the chance of securing funding or to meet the requirements of senior clinicians and academics (with no recognition of the benefits of their involvement).

Moreover, there is a stark discrepancy between the assessment of Service Users and other workstream members. This applies both to their assessments of the extent to which Service Users' input was valued and supported, and to their assessments about the impact of Service Users' involvement. While most Service Users felt under-valued, sometimes marginalised, and prevented from making the level of impact they judged they could have made, the majority of Chairs, Workstream Support Officers and Other Workstream Members felt that Service Users had made a significant contribution and impact (though a minority of Chairs felt the impact had been patchy and, with more support, could have been greater). In our experience, this degree of discrepancy is unusual and worth reflecting upon.

We can speculate as to the reasons for this discrepancy. This evaluation is based on the perceptions of interviewees. It may be that Service Users themselves are in the best position to judge impact: this is a position that many who advocate Service User involvement would take. Certainly, only Service Users can judge whether the experience felt 'good' or not (and in this case, it usually did not). However, it could be that Service Users made an impact which was not fully communicated to them. Another reason could be that Service Users had

higher expectations of the impact they could or should make, than did other workstream members, leading to lower satisfaction levels.

As a cancer charity, Macmillan Cancer Support's main target group for engagement is people affected by cancer. It is important to recognise that any retention issues that arise may be due to recurrence of disease, the demands of active treatment, changes in caring responsibilities, and/or Service Users passing away, rather than to factors which can arise with any Service User engagement (e.g. loss of interest, not always feeling heard, a lack of financial support)⁸. For example, Macmillan Cancer Support feels it has a comprehensive and fair reimbursement policy and the project officer dealing with expenses for the Peer Support Group received no queries or complaints about expenses during this time.

We cannot be sure of the cause of a discrepancy between the views of Service Users' and professionals. However, the data do suggest a uniform Service User view concerning the inconsistency of systems and processes to involve people. This suggests that impact and outcomes are unlikely to have been optimised and lends weight to Service Users' subjective views about lack of impact.

In section 2, we identified models of involvement that seemed to be operating within different workstreams (active strategic involvement, implementing and consultation). Compared to our experience elsewhere, there has been a worrying degree of inconsistency in the models for, and approaches towards, involvement taken across different workstreams. This may have led to a poor overall degree of involvement across the programme. We see consultation as being the lowest level of Service User involvement (in that, by comparison to the other models, it is likely to make the least use of Service Users skills and experience and provide them with the least learning and development opportunities) and active strategic involvement as the highest level.

In the context of the lack of adequate systems and processes in place to support involvement, the involvement that has taken place seems to have been at the 'lower' end. If Service Users are unsure what role they are supposed to be playing, struggling to understand processes or content, or inadequately trained, they are likely to find it difficult to be 'heard'. Those who speak up may be perceived as difficult to deal with and therefore marginalised, while those who don't may get bored and withdraw. At the same time, those involved in an initiative may be motivated to ensure that Service Users are comfortable with the work they are doing and may avoid assigning them to more challenging work in the absence of inadequate support structures to facilitate this (or awareness of Service Users' capabilities).

A lack of effective structures and support for Service User engagement can create a vicious circle. Service Users may feel undervalued and, as a result, cease participating fully. This would lead to them not having a major impact, which undermines the perceptions of other

⁸ Further, it is not always appropriate to share the reason for a Service User ceasing to participate with other users. This can lead to users forming their own ideas as to the reasons behind someone 'dropping out', possibly concluding that it is to do with a lack of support.

workstream members as to the value of Service User impact. This leads to Service Users not being integrated into an initiative at the higher end of our spectrum of Service User involvement.

One Chair reported that Service User impact was undermined by Service Users ceasing communication with the workstream (and thus being replaced). One wonders what might have happened if Service Users had been better supported to be involved. This ‘vicious circle’, whereby Service Users were driven to a ‘lower level’ of involvement, may be one cause of the perception that a ‘Macmillan agenda’ drove phase one of the NCSI (see section **Error! Reference source not found.**).

Many users had previous experience of user involvement, either within Macmillan, Cancer Networks, or NHS Trusts, and had experienced varying levels of support and impact. User involvement can also bring back feelings Service Users may have experienced as a result of their illness and treatment. For example, if a Service User’s ideas are questioned, debated, or not taken forward, this may bring up feelings of being ‘disempowered’, ‘isolated’ or ‘abandoned’: words often used by users to describe their cancer experience. In this context, it is particularly important to take steps to ensure that Service User involvement is managed effectively and sensitively, including managing the expectations of Service Users as to the likely impact of their involvement.

In order to ensure effective Service User involvement in the future, we suggest that Macmillan Cancer Support consider producing written guidance for Service User involvement in future initiatives, to ensure there is shared understanding of the involvement model.

This guidance would address the key issues identified in this report, as follows:

- A vision for user involvement. Service User engagement in an initiative is likely to be more effective and rewarding if it is guided by a vision/plan (co-developed with Service Users) from the outset. The vision needs to be communicated to all those involved in the initiative, both professionals and Service Users. User involvement must be planned carefully in advance, thinking through appropriate types of involvement, levels of involvement and the rationale for involvement. In some cases, there may be particular challenges to involving users, for example where the subject matter of a workstream or project is clinical and involves a high degree of specialist knowledge.
- Clarity of role. To address the issues identified in sections 5.2.1 and **Error! Reference source not found.**, Service Users and other stakeholders need a shared understanding of the Service User role. The organisation should work with Service Users to develop a clear specification for the role that Service Users should play. There are two types of consideration here, as follows:

- The **function** of a person's involvement. Are Service Users intended solely to share their own experiences? Keep discussions 'patient-centred' by asking 'challenging questions'? Provide information or be a resource for the Service User experience based on the views of people in wider networks (thus being more 'representative')? All these are valid. It's a question of stating clearly which applies.
 - The **'level'** of input expected. To what degree are Service Users expected to input at a strategic or advisory level (i.e. contributing to decision making)? Or are they expected to play a part in designing and delivering project/activity based initiatives? (It should be recognised that the skills involved in each of these are not the same).
- Capacity-building amongst non-Service Users. More could and should be done with Chairs, workstream members and health professionals, at an early stage of participation, to raise their awareness and understanding of the benefits and processes of Service User engagement. This includes briefing all those participating in an initiative as to the relevant contribution that can be made by Service Users participants. There should be mandatory training in Service User engagement for people in senior roles within initiatives involving Service Users (including Workstream Chairs in this instance), and indeed for as many people involved in initiatives as possible. This would reduce the chance of Service Users feeling that their contribution was under-valued (see section 5.1.1) and would be likely to contribute to Chairs managing Service User involvement effectively (see section 5.2.2).
 - Identification and recruitment. To address the issues identified in section 5.2.4 identification and recruitment of Service Users needs to be planned with Service Users so as to be transparent (so people know why and how they were allocated within an initiative) and provide choice. The latter should be based on allowing users to identify where they can have the most impact, where they feel most comfortable, and perhaps also where they feel they will have most opportunity to develop new skills and capacities.
 - Communication. There need to be systems in place for communicating to Service Users, clearly and in a timely manner, decisions as to the future direction and structures of an initiative (particularly those that will have a direct impact on Service Users), as well as the nature of practical support arrangements. (See section 5.2.6).
 - Practical support. More needs to be done to provide adequate practical support for Service Users, to enable them to participate despite any logistical barriers. This would include provision of documentation in a variety of formats, and in a timely manner, taking their needs into account in the timing, duration and location of meetings, provision of ICT facilitates and support in using them. (See sections 5.2.6 and 5.3.5). Particularly in the context of cancer, it is important to ensure that Service Users are enabled to participate in a range of ways, reducing reliance on attending meetings: particularly for those users who are not well or are caring for someone and may have to travel long distances to attend. It would also be beneficial to ensure that several Service Users are involved in each capacity, to provide continuity should one Service User be forced to withdraw.

- Learning and development for Service Users. There is a need to provide adequate learning and development opportunities for Service Users. This would begin with a clear induction process (covering expectations, background information and role including whether Service Users are representing themselves or a wider body of interest, and how to operate effectively in meetings see section 5.2.5) and include ongoing opportunities to reflect on their own learning. Forums for Service Users should be developed where people can ask questions, raise concerns, share experiences and good practice, and receive current information about initiatives. The NCSI Peer Support Group was intended to fulfil this function, and the evaluation shows it could have been more effective (see section 5.2.7). Such a forum needs to include opportunities for Service Users to exchange information between themselves (with no Macmillan Cancer Support or other interest groups present). Moreover, there should be ongoing opportunities for people to develop the skills, behaviours and understanding necessary to be effective (see also Table 6.1).
- Resourcing. Macmillan Cancer Support might consider investigating what mechanisms and resources it can create to ensure that ideas generated by Service Users can be progressed. For example, this might involve the creation of a specific fund for Service User innovations. (Care should be taken to avoid the potential further to marginalise Service Users: there is a risk that other workstream members would regard the existence of resources dedicated to Service User generated ideas as implying that it is not necessary/appropriate to support such ideas from mainstream resources).
- Monitoring and performance management. Adequate systems for monitoring and reporting on the process and outcomes of Service User engagement (to Service Users, and those responsible for overseeing their engagement) are needed to ensure that all participants have a shared understanding of the impact of Service User engagement (see section **Error! Reference source not found.**). This should be part of mainstream reporting on progress and risk management, rather than seen as a separate ‘specialist’ requirement.

Appendix One
Discussion guides

Discussion guide
Service Users
Focus groups

Thank the respondent/participants for coming and tell them:

- The purpose of the group. It's part of an evaluation of the NCSI Service User Involvement model. We're looking at: how effectively the NCSI is involving Service Users; the impact that Service Users are having on the NCSI; and what is working and what is working less well with regards to NCSI Service User involvement.
- What else we're doing: interviewing Service Users, interviewing Chairs of workstreams, interviewing other members of workstreams.
- That we'll be producing a report for Macmillan Cancer Support in the autumn.
- How long you expect the group to last (up to an hour and a quarter).
- That you are audio-recording the group. The reason for this is because taking notes is too difficult at the same time as facilitating. The only people who will hear the recording are the researchers present and a transcriber. Once the recording has been transcribed, it will be deleted. The transcription will only be seen by the research team and will be destroyed once the research is complete. We will use their comments in our report to Macmillan Cancer Support in the autumn. Though we may quote them directly, we won't identify them in the report.
- That there is no need to speak differently because of the recording. They can ignore the microphone and speak normally.
- That it's best if they take turns to speak. If too many people speak at once, it's hard to make out what's being said.
- That we want to hear everyone's views and they shouldn't feel inhibited about speaking up if they disagree with what most people are saying.

Background information

1. *(Introduce this by saying you'd like to go round the table with each person taking their turn to introduce themselves. As well as helping everyone get to know each other, this helps the transcriber to get to know people's voices and where they're sitting in the room).* Background information: name, workstream, when they became a Service User.
2. What has been the nature of your involvement with the NCSI to date?
Prompts: attending Peer Support Group meetings, attending workstream meetings (which workstream).

Service User engagement model

3. In what way does your workstream involve you (and other Service Users)? *(If they struggle to answer this, tell them how it works in **your** workstream and ask about similarities and differences).*

Role of Service Users

4. What is your understanding of your role as a Service User?
5. Why do you think Service Users are involved in the NCSI? What do you think the benefits are?
6. What do you think the Chair of your workstream understands your role to be?
If the answer doesn't align with the answer to 4, explore with them how this may have arisen, whether and how it is being addressed (by them and by others) and what more could be done to address it.
7. What do other members of your workstream understand your role to be?
If the answer doesn't align with the answer to 4, explore how this may have arisen, whether and how it is being addressed (by them and by others) and what more could be done to address it.
8. We are interested in exploring further how you see your role and how others see it. To what extent do you agree that:
 - a. Service Users should draw on their existing understanding of the needs and views of people affected by cancer related to their workstream;
 - b. They should act as a link between the workstream and relevant people affected by cancer;
 - c. They should provide input to the workstream based on their own views and needs.

9. (If they agree to any extent with the second statement). How do you keep in touch with the experiences of other people affected by cancer? What difficulties do you experience with this? Could the NCSI do more to assist you with this? If so, what might it do?
10. Have you ever experienced difficulties in reconciling your role representing people affected by cancer with working with workstream participants? If so, tell me about what happened, what you experienced, how you managed it and how it was addressed (if at all) by other workstream participants.

Impact of Service User involvement

11. What impact has your involvement had so far on the activities of the workstream (e.g. different activities, wider range of activities)? What impact do you think it is likely to have over the life of the project? Are there any changes you would like made that would enable you to make more of an impact? *(Use workstream progress report as a prompt to explore the impact the user has had on each activity, though bear in mind the report may be out of date. If appropriate, ensure the consultee knows that we can't guarantee their suggestions will be implemented).*
12. What impact has your involvement had so far on how the workstream contributes to the overall NCSI programme? What impact do you think it is likely to have over the life of the project? Are there any changes you would like made that would enable you to make more of an impact? *(Use workstream's list of planned outputs as prompts. How is the Service User contributing to each of these outputs?)*
13. What impact has your involvement had so far on the way the workstream operates and conducts its business?
14. What impact has your involvement had so far on the efficiency of the workstream? By efficiency, I mean things like the speed at which it works and the amount of people's time and other resources it uses to achieve what it achieves. *(You may need to probe gently here and reassure them that we don't think it's bad if their involvement has slowed things down or meant that more resources are used, as this might be considered an acceptable trade-off for the benefits their involvement brings).* Are there any changes you would like made that would improve efficiency?

15. What impact has your involvement had so far on you? What impact do you think it is likely to have over the life of the project? (E.g. increased/ decreased self-confidence, satisfaction with the health service, empowerment, stress, fatigue, sense of being listened to/heard, sense of making a contribution)? How could this be improved? Are there any changes you would like made that would increase the positive impacts on you and/or decrease the negative ones?
16. To summarise this section, could you tell me whether you agree or disagree with each of the following statements:
- In this workstream, Service Users are prime movers shaping aspects of what is being achieved.
 - In this workstream, Service Users support sub-groups of workstream members to shape aspects of what is being achieved.
 - In this workstream, Service Users help workstream members to understand user perspectives on specific aspects of what is being achieved.
 - In this workstream, Service Users raise workstream members' awareness that there is a user perspective on specific aspects of what is being achieved.
 - In this workstream, Service Users are making no discernable impact on what is being achieved.

Facilitators and barriers to Service User involvement

17. What aspects of the way your workstream operates help you to make a contribution to the workstream? How do they help?
18. What aspects of the way your workstream operates hinder you in making a contribution to the workstream? How do they help and how could this be improved?
19. What skills do you think you need to participate effectively in the NCSI and to what extent have you got these skills already? Do you want/need training in any specific skill areas? (Prompts:
- Communication and presentation skills;
 - Knowledge and understanding of healthcare;
 - Analytical skills;
 - The skills involved in being a 'critical friend' (e.g. Being able to ask challenging questions in a non-threatening way);
 - Influencing skills).

14. What other support have you been offered and have you received around your participation in the NCSI? (Prompts: formal peer support, informal peer support, training)? What difference is this making? Would you like any additional support? If so, what support would you like (meaning both support with what and the nature of that support)?
20. Overall, do you personally feel ‘heard’ within the NCSI? Is your involvement adequately prioritised, supported and resourced?
21. Overall, do you think people affected by cancer are ‘heard’ within the NCSI?

Anything else

22. Is there anything else you want to make me aware of before we finish?

Thank the respondent/participants for their time and contribution.

Let them know that they can email you or rachel@papworth.info if they want to add anything.

Discussion guide
Service Users
One-to-one

Thank the respondent/participants for coming and tell them:

- The purpose of the interview. It's part of an evaluation of the NCSI Service User Involvement model. We're looking at: how effectively the NCSI is involving Service Users; the impact that Service Users are having on the NCSI; and what is working and what is working less well with regards to NCSI Service User involvement.
- What else we're doing: undertaking focus groups with Service Users, interviewing Chairs of workstreams, interviewing other members of workstreams.
- That we're aware that the workstreams have been dissolved and this consultation will collect their views on what's happened to date.
- That we'll be producing a report for Macmillan Cancer Support in the autumn.
- How long you expect the interview to last (up to an hour).
- That you will be writing up your notes for the research team to use and will give them an opportunity to comment on them, suggest amendments and approve them. *Make sure you've got their email address.*
- Only the research team will see these notes. We will use their comments in our report to Macmillan Cancer Support in the autumn. Though we may quote them directly, we won't identify them in the report.

Background information

1. Background information: name, workstream, when they became a Service User.
2. What has been the nature of your involvement with the NCSI to date?
Prompts: attending Peer Support Group meetings, attending workstream meetings (which workstream).

Service User engagement model

3. In what way has your workstream involved you (and other Service Users)? *(If they struggle to answer this, tell them how it works in **your** workstream and ask about similarities and differences).*

Role of Service Users

4. What is your understanding of your role as a Service User?
5. Why do you think Service Users are involved in the NCSI? What do you think the benefits are?
6. What do you think the Chair of your workstream understands your role to be?
If the answer doesn't align with the answer to 4, explore with them how this may have arisen, whether and how it is being addressed (by them and by others) and what more could be done to address it.
7. What do other health professionals on your workstream understand your role to be?
If the answer doesn't align with the answer to 4, explore how this may have arisen, whether and how it is being addressed (by them and by others) and what more could be done to address it.
8. We are interested in exploring further how you see your role and how health professionals see it. Please rate the extent to which you agree with the following statements and the extent to which you think health professionals might agree with them. A rating of 0 indicates total disagreement and a rating of 5 indicates total agreement. If you don't know, just say. *(Use the table on the last page of this document. Where the respondent rates how a specific person sees their role, write that person's name and/or role in the top of the column).*
9. (If they rated the second statement as anything other than 0 in any column). How do you keep in touch with the experiences of other people affected by cancer? What difficulties do you experience with this? Could the NCSI do more to assist you with this? If so, what might it do?

10. Have you ever experienced difficulties in reconciling your role representing people affected by cancer with working with workstream participants? If so, tell me about what happened, what you experienced, how you managed it and how it was addressed (if at all) by other workstream participants.

Impact of Service User involvement

11. What impact has your involvement had so far on the activities of the workstream (e.g. different activities, wider range of activities)? What impact do you think it is likely to have over the life of the project? Looking back, what could have been done differently that would have enabled you to make more of an impact? *(If appropriate, ensure the consultee knows that we can't guarantee their suggestions will be implemented).*
12. What impact has your involvement had on how the workstream has contributed to the overall NCSI programme? What impact do you think your involvement is likely to have on the overall NCSI programme over the life of the project? Looking back, what could have been done differently that would have enabled you to make more of an impact?
13. What impact has your involvement had on the way the workstream operates and conducts its business?
14. What impact has your involvement had on the efficiency of the workstream? By efficiency, I mean things like the speed at which it works and the amount of people's time and other resources it uses to achieve what it achieves. *(You may need to probe gently here and reassure them that we don't think it's bad if their involvement has slowed things down or meant that more resources are used, as this might be considered an acceptable trade-off for the benefits their involvement brings).* Looking back, what could have been done differently that would have improved efficiency?
15. What impact has your involvement had so far on you? What impact do you think it is likely to have over the life of the project? (E.g. increased/decreased self-confidence, satisfaction with the health service, empowerment, stress, fatigue, sense of being listened to/heard, sense of making a contribution)? How could this be improved? Looking back, what could have been done differently that would have increased the positive impacts on you and/or decreased the negative ones?
16. To summarise this section, could you tell me whether you agree or disagree with each of the following statements:
 - f) In this workstream, Service Users have been prime movers shaping aspects of what is being achieved.

- g) In this workstream, Service Users have supported sub-groups of workstream members to shape aspects of what is being achieved.
- h) In this workstream, Service Users have helped workstream members to understand user perspectives on specific aspects of what is being achieved.
- i) In this workstream, Service Users have raised workstream members' awareness that there is a user perspective on specific aspects of what is being achieved.
- j) In this workstream, Service Users have made no discernable impact on what is being achieved.

Facilitators and barriers to Service User involvement

17. What aspects of the way your workstream operated helped you to make a contribution to the workstream? How did they help?
18. What aspects of the way your workstream operated hindered you in making a contribution to the workstream? How did they help and how could this have been improved?
19. What skills do you think you need to participate effectively in the NCSI and to what extent have you got these skills already? Do you want/need training in any specific skill areas? (Prompts:
 - Communication and presentation skills;
 - Knowledge and understanding of healthcare;
 - Analytical skills;
 - The skills involved in being a 'critical friend' (e.g. Being able to ask challenging questions in a non-threatening way);
 - Influencing skills).

15. What other support have you been offered and have you received around your participation in the NCSI? (Prompts: formal peer support, informal peer support, training)? What difference is this making? Would you like any additional support? If so, what support would you like (meaning both support with what and the nature of that support)?
20. Overall, do you personally feel ‘heard’ within the NCSI? Is your involvement adequately prioritised, supported and resourced?
21. Overall, do you think people affected by cancer are ‘heard’ within the NCSI?

Anything else

22. Is there anything else you want to make me aware of before we finish?

Thank the respondent/participants for their time and contribution.

Let them know that they can email you or rachel@papworth.info if they want to add anything.

Question 8

0=completely disagree. 5=completely agree. DK=don't know.

	How you see your role	How your Workstream Chair sees your role	How (a specific workstream member) sees your role ⁹	How (a specific workstream member) sees your role ⁹	How (a specific workstream member) sees your role ⁹	How (a specific workstream member) sees your role ⁹	How (a specific workstream member) sees your role ⁹	How other workstream members see your role
My role is to draw on my existing understanding of the needs and views of people affected by cancer related to my workstream								
My role is to act as a link between the NCSI and relevant people affected by cancer								
I can only provide input to the NCSI based on my own views and needs								

⁹ Write the name and/or role of the member in this box

Discussion guide
Workstream members
One-to-one

Thank the respondent for agreeing to meet with/speak with you and tell them:

- The purpose of the interview. It's part of an evaluation of the NCSI Service User Involvement model. We're looking at: how effectively the NCSI is involving Service Users; the impact that Service Users are having on the NCSI; and what is working and what is working less well with regards to NCSI Service User involvement.
- What else we're doing: interviewing Service Users, undertaking focus groups with Service Users, interviewing Chairs of workstreams, interviewing other members of workstreams.
- That we're aware that the workstreams have been dissolved and this consultation will collect their views on what's happened to date.
- That we'll be producing a report for Macmillan Cancer Support in the autumn.
- How long you expect the interview to last (up to 90 minutes for a face-to-face interview, up to an hour for a telephone interview).
- That you will be writing up your notes for the research team to use and will give them an opportunity to comment on them, suggest amendments and approve them. *Make sure you've got their email address.*
- Only the research team will see these notes. We will use their comments in our report to Macmillan Cancer Support in the autumn. To let you know if they say anything they would like kept anonymous or confidential.

Background information

1. Background information: name, job title, workstream

Service User engagement model

2. Within your workstream, who has been responsible for Service User engagement (name and job title)? What other roles did that person have within the workstream?
3. Please describe how your workstream has involved Service Users. In what ways have Service Users participated in the workstream? How has your workstream resourced and supported Service User participation?
*(If they struggle to answer this, tell them how it worked in **your** workstream and ask about similarities and differences).*
4. To what extent was this model a result of the specific focus of your workstream? How did the focus of your workstream affect how you involved Service Users?
5. To what extent and how did the approach to involvement of Service Users in this workstream fit within a wider NCSI strategy for public and patient engagement?

Role of Service Users

6. What is your understanding of the role of a Service User (i.e. what are their main functions)?
7. Why do you think Service Users are involved in the NCSI? What benefits do they bring?
8. What do you think the Service Users that were on your workstream understand their role to be?
If the answer doesn't align with the answer to 6, explore with them how this may have arisen, whether and how it was addressed (by them and by others) and what more could be done to address it.

9. What did other members of your workstream understand the role of the Service Users to be?

If the answer doesn't align with the answer to 6, explore how this may have arisen, whether and how it was being addressed (by them and by others) and what more could be done to address it.

10. We are interested in exploring further how you see the Service User role and how other health professionals see it. Please rate the extent to which you agree with the statements in this table and the extent to which you think other health professionals might agree with them. A rating of 0 indicates total disagreement and a rating of 5 indicates total agreement. If you don't know, we'll just write DK in the box. *(Use the table on the last page of this document. If the respondent wants to rate how a specific person sees their role, write that person's name and/or role in the top of the column).*

Impact of Service User involvement

11. Did you monitor/record the outcomes of Service User involvement in your workstream? If so, how did you do this and is there any documentation that we can access?
12. What impact did Service User involvement have on the activities of the workstream (e.g. different activities, wider range of activities)? Looking back, what could have been done differently that would have enabled them to make more of an impact? *(If appropriate, ensure the consultee knows that we can't guarantee their suggestions will be implemented)*
13. What impact did Service User involvement have on how the workstream contributed to the overall NCSI programme? What impact do you think it is likely to have on the overall NCSI programme over the life of the project? Looking back, what could have been done differently that would have enabled them to make more of an impact?
14. What impact did Service User involvement have on the way the workstream operated and conducted its business?
15. What impact did Service User involvement have on the efficiency of the workstream? By efficiency, I mean things like the speed at which it works and the amount of people's time and other resources it uses to achieve what it achieves. Looking back, what could have been done differently that would have improved efficiency?
16. What impact has Service User involvement had on Service Users? What impact do you think it is likely to have over the life of the project? (E.g. increased/decreased self-confidence, satisfaction with the health service,

empowerment, stress, fatigue, sense of being listened to/heard, sense of making a contribution)? How could this be improved? Looking back, what could have been done differently that would have increased the positive impacts on them and/or decreased the negative ones?

Facilitators and barriers to Service User involvement

17. What aspects of the way your workstream operated helped Service Users to make a contribution to the workstream? How did they help?
18. What aspects of the way your workstream operated hindered Service Users in making a contribution to the workstream? How did they hinder it and what could have been done differently to reduce this effect?
19. Did Service Users ever face difficulties in reconciling their role representing people affected by cancer with working with the workstream participants? If so, tell me about what happened and how it was addressed.
20. What skills do you think Service Users need to participate effectively in the NCSI and to what extent have those who were on your workstream got these skills already? Do they need training in any specific skill areas? (Prompts:
 - Communication and presentation skills;
 - Knowledge and understanding of healthcare;
 - Analytical skills;
 - The skills involved in being a 'critical friend' (e.g. Being able to ask challenging questions in a non-threatening way);
 - Influencing skills).
16. What other support for their participation is available to Service Users? (Prompts: formal peer support, informal peer support, training)? What difference is this making? Do they need further support? What more might be offered?
21. Overall, to what extent are people affected by cancer 'heard' within the NCSI?

22. To summarise this section, could you tell me whether you agree or disagree with each of the following statements:

- k) In this workstream, Service Users were prime movers shaping aspects of what is being achieved.
- l) In this workstream, Service Users supported sub-groups of workstream members to shape aspects of what was achieved.
- m) In this workstream, Service Users helped workstream members to understand user perspectives on specific aspects of what was achieved.
- n) In this workstream, Service Users raised workstream members' awareness that there is a user perspective on specific aspects of what was achieved.
- o) In this workstream, Service Users made no discernable impact on what was achieved.

Anything else

23. Is there anything else you want to make me aware of before we finish?

Thank the respondent/participants for their time and contribution.

Let them know that they can email you or rachel@papworth.info if they want to add anything.

Question 8

0=completely disagree. 5=completely agree. DK=don't know.

	How you see the role of Service Users	How your Workstream Chair sees their role	How (a specific workstream member) sees their role ¹⁰	How a (specific) workstream member sees their role ⁹	How (a specific workstream member) sees their role ⁹	How (a specific workstream member) sees their role ⁹	How (a specific workstream member) sees their role ⁹	How other workstream members see their role
Service Users should draw on their existing understanding of the needs and views of people affected by cancer related to my workstream								
They should act as a link between the NCSI and relevant people affected by cancer								
They should provide input to the NCSI based on their own views and needs								

¹⁰ Write the name and/or role of the member in this box