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The National Cancer Registration and Analysis Service Future Events Stakeholder Engagement Report

July 2019

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Introduction

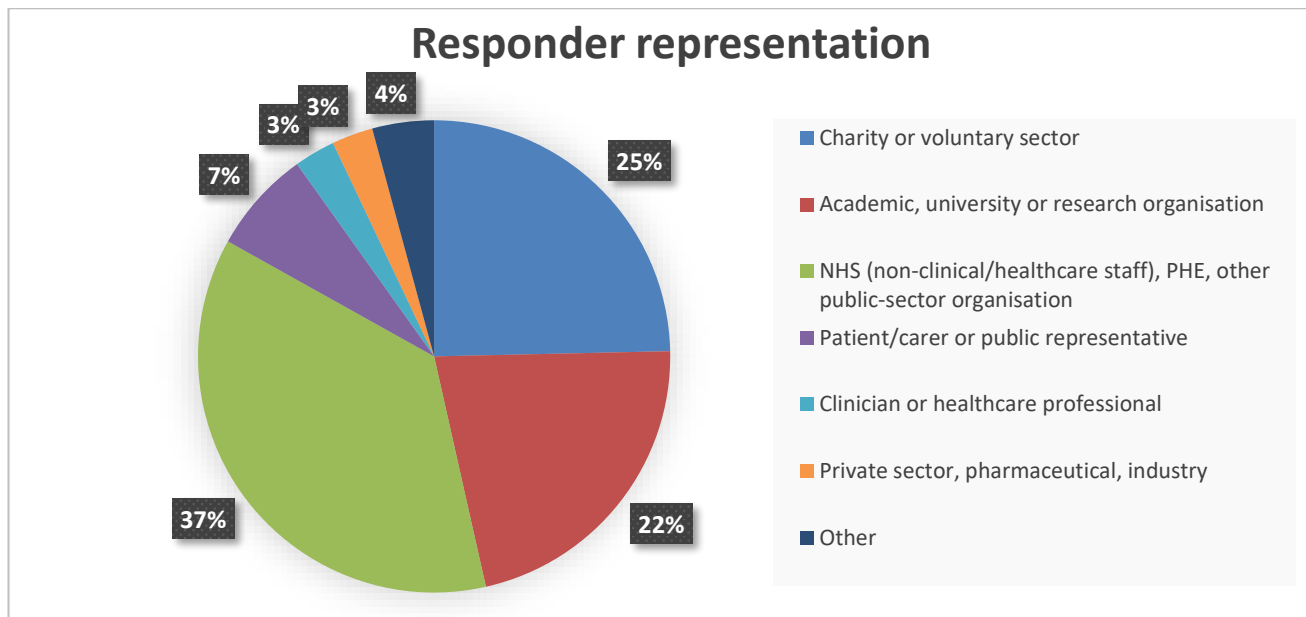
In 2018 Public Health England's National Cancer Registration and Analysis Service, supported by PHE's Cancer Board, took the decision to postpone the annual *Cancer Services, Data and Outcomes Conference*. In the preceding years, the conference was an important fixture for the cancer data community and was very well attended. In 2018, 80% of delegates said they felt the conference was 'good'. However, feedback also raised some concerns about whether the conference reflected the wide range of interests of those working with cancer data. And so, we sought the views of our stakeholders and previous conference attendees to help us understand how future conferences can better reflect the needs of all those working with cancer data in the ever-changing cancer landscape.

This document is a summary of the feedback we received from the online survey (January 2019) and the stakeholder workshops (April 2019) outlines how we will implement this feedback.

We would like to thank everyone who responded to the survey and who took part in the workshops. The feedback received has been invaluable in helping us to understand the expectations, needs and views of our stakeholders and to help shape our future conferences and events.

Stakeholder survey feedback summary

The survey was sent to 600 previous conference delegates who had subscribed to be contacted for further information. We received 142 completed survey responses (127 online responses, 13 offline responses). The responses were representative of the range and proportion of delegates from different organisations who attend the annual cancer data conference.



Key findings

When asked about the preferred format and frequency of future events 49% of respondents wanted an annual 2-day conference with 24% preferring a range of 1-day events. Other responses asked for a 1-day roadshow covering the same content in different geographical locations (12%) and a longer event (e.g. 3-4 days) every 2 years (8%).

The survey asked respondents to identify the components that are most important to them. The top six components included:

1. Hearing about the latest in how data has impacted on clinical and service delivery
2. Hearing about the latest in cancer data analysis
3. Networking
4. The opportunity to present and showcase your work
5. Hearing about innovation from academic studies using cancer data
6. Patient and public involvement

Respondents were also asked to suggest one improvement the team could make to any future cancer data event. The free text answers were analysed and grouped into themes as shown in Table 1.

Table 1. One key improvement

Theme	Number of responses
Venue – including location and layout	19
Content ideas	19
Broadening international input	17
Better defined patient involvement	14
More clearly defined objectives and themes	14
More interactive sessions	14
Volume of content – repeating content, accessing sessions/information after the event	12
Improved opportunities for networking	10
Catering	10
Keynote speakers	10
Multiple stakeholder input	8
Impact aspect of research/projects	8
More frequent events	5
Marketing and communications	4
Quality of presentations	3
Accessibility of content	2
Following up previous presentations or work	2

- The survey results confirmed that people still want an annual cancer data conference
- That the focus of the conference should be to share knowledge about the latest developments in cancer data collection, analysis and research and to understand how this has impacted on patient care and clinical delivery
- The survey also raised some differences of opinion which we then took forward to discuss in more detail at the workshops.

Stakeholder workshops feedback summary

Everyone who completed the online survey and indicated they were willing to be involved in the workshops was invited to attend one of the four sessions. Telephone calls were offered to individuals who were unable to make the sessions in person.

Four workshops were held, three in London and one in Leeds in April 2019. They were attended by 27 people representing the range of stakeholders the conference attracts; clinicians, patients, carers, campaign groups, charities, academia, industry and Public Health England staff. A full list of participants can be found in Appendix 1.

Workshop format

The workshops were structured to address the important findings from the survey, allow participants to raise queries and to gather further input to improve future conferences.

The following is a summary of the discussions, suggestions and outcomes of the workshops.

Headlines

- The conference is a widely well-regarded event that provides a unique opportunity for those working in the field to come together to discuss and learn about what is new in cancer data
- The conference should continue
- Participants welcomed the opportunity to discuss the conference in more detail and to put forward their thoughts on how it can be improved
- Some stakeholders did not understand and/or agree with the rationale for postponing the conference
- Networking and the opportunity to make new contacts and collaborations is viewed as critical to the success of the conference
- The conference does not need to change dramatically but instead small modifications and updates would ensure the conference remains fit for purpose and relevant to audiences across the cancer community
- Defining the purpose of the conference would help to develop and define the content, appeal to those who are not yet familiar with it and support those attending to have a clearer view of what they can get out of it

Many positive reflections and comments were made about the conference, in particular;

- The importance of its role as the only conference to bring together the cancer data community
- The breadth of the programme which is inclusive of all aspects of the data journey and expertise
- Inclusivity in relation to audience and topics
- Being a platform for junior analysts to present
- Including the voice of the patient
- Being a vehicle for innovation

Some criticisms and/or areas for improvement were expressed too. These being;

- Being too PHE and England centric

- A lack of pre- and post-conference information
- Being in the same venue year after year
- For some, conflicting or confused programming
- A lack of clinical and local representation
- Missing the connection between research and what it means for cancer services and improving outcomes for patients
- And a small number of people felt in the last few years it had lacked a sense of anything new

Workshops discussions

Using the survey feedback, we identified four key areas to better explore the differences in opinion and queries raised. Workshops attendees were asked to discuss:

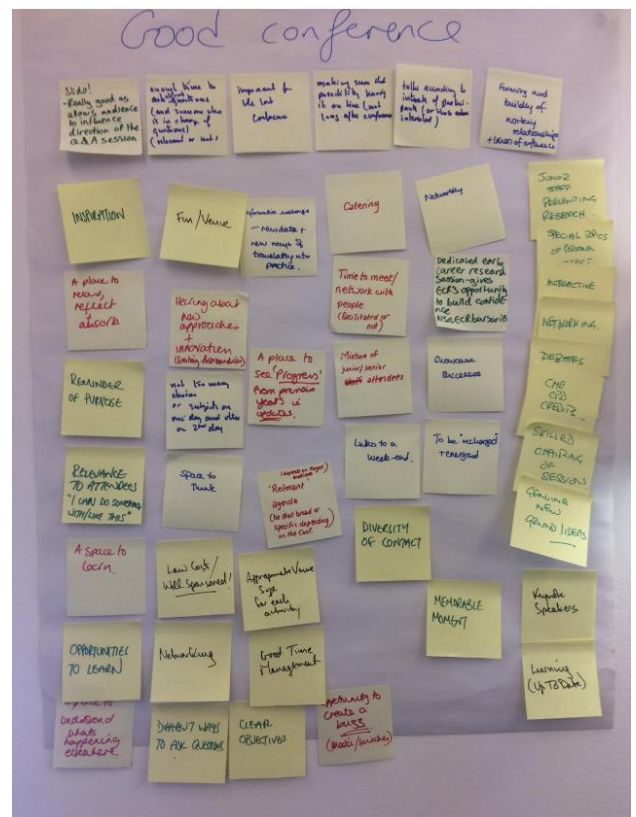
- What makes a good conference?
- Networking
- Patient and public involvement
- Marketing and communications

What makes a good conference?

The components that make up a good conference vary between audiences. The cancer data conference appeals to a wide range of individuals and organisations. Many workshop attendees felt the breadth of the audience has been a very positive aspect of the conference in past years. There were several other clear themes that resonated across all the workshops.

Common suggestions:

- Updated technology – submit questions electronically, download presentation slides post event, HTML version of programme, digital posters, conference app, digital agenda that is accessible by smartphone
- Clear objectives and reminder of purpose
- Clearly defined event themes and parallel session topics
- Range of session types - presentations, speed talks, interactive sessions, discussion
- Conference programme available well in advance of the event
- Hearing about innovation as well as new and exciting content
- Good session chairs and high-quality speakers
- Revisit previous conference presentations and speakers for progress updates
- CPD accreditation to encourage more NHS and clinical staff to attend
- Showcase the successes
- Actions for delegates to take away
- Accessible content including producing lay summaries where relevant
- Consider the amount of content and length of days



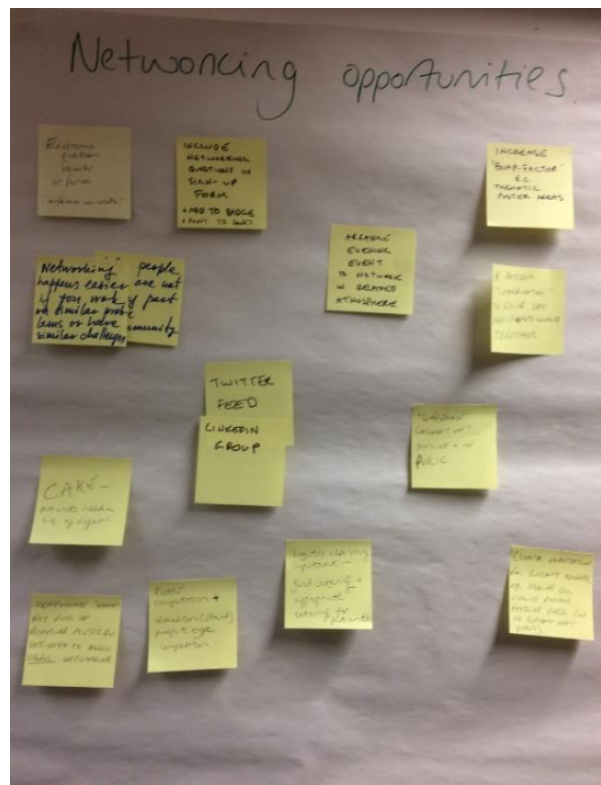
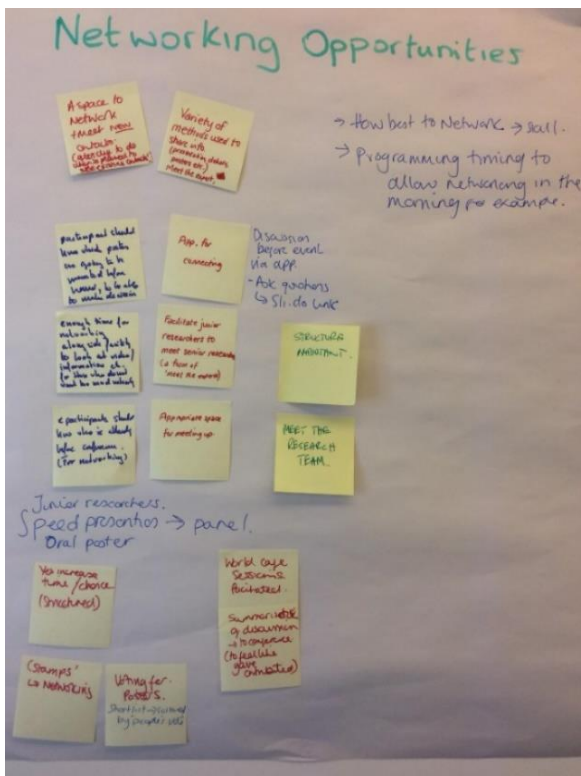
Networking

Networking was ranked as one of the top six components of a conference by 68% of the survey respondents. Many workshop attendees agreed that this is a critical part of the conference experience and for some, almost exclusively the reason they attend.

To improve networking the workshop attendees suggested that there should be more time and opportunities in the programme for delegates to meet with others. Additionally, more structured networking would be welcomed by many; allowing people to find others more quickly and helping start conversations, without being over directive.

Common suggestions:

- Reviewing the setup, space and time dedicated to poster viewing (see below)
- Circulation of delegate list prior to event to facilitate connections
- Ensuring enough down-time is factored into the programme
- Using LinkedIn and other social media platforms to facilitate connections before and after the event
- Dedicated zones for people to meet and discuss specific topics
- Open question and discussion boards
- “Meet the research team” 5-minute introduction their topic of and open Q and A
- Creating comfort areas for people to sit and network
- Evening and social activities as another opportunity to meet and network
- Larger name badges



Posters

Poster viewing often forms a key part of networking opportunities. Consistent feedback suggested that in recent years the setup and time dedicated to poster viewing was not effective. Workshop attendees agreed that further thought was needed to ensure that the posters become a more significant part of the

conference and that delegates have enough time to view them and to speak with the authors. The attendees suggested introducing digital posters and providing a dedicated time as part of the programme for poster viewing and ensuring there is sufficient space to move around the posters and making more of the poster competitions.

Patient, Carer and Public Involvement

As the custodians of cancer data for England, it is important that we improve awareness of how patient information is collected, shared and used to make improvements in cancer care and outcomes. It is also essential that we involve patients, carers and the public in our work and the conference. Therefore, it is important that the voice of people affected by cancer is heard at the conference and moreover that patients, carers and the public have a platform to express their views on the collection and use of cancer data.

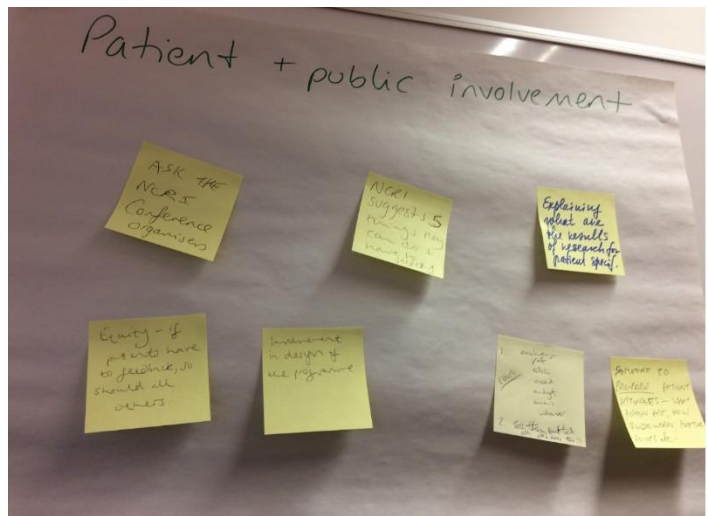
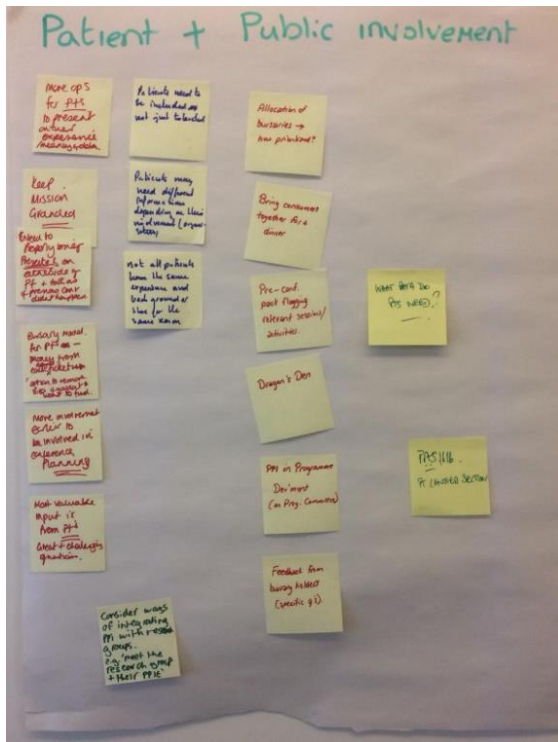
Previously, PHE has provided bursaries for up to 50 patients, carers and members of the public to attend the conference. The bursary covers the delegate fee, conference dinner, the individual's travel and overnight accommodation if required, and any additional out-of-pocket expenses within the PHE expenses policy. We will also provide a bursary for an individual's carer if required. In previous years patient representatives have been involved in some aspects of the conference including programme planning, abstract shortlisting, poster prize selection, speaking, acting as session chairs and running workshops.

The discussions at the workshops highlighted that the voice of patients, carers and members of the public at the conference is valued, but for some the aim of patient and public involvement wasn't always clear. Others said the conference could make more opportunities for patients, carers and the public to be involved but there was mixed opinion as to whether we should be requesting bursary delegates take on tasks or responsibilities, or whether this was unfair as other conference attendees are not asked to do this.

Common suggestions:

- Broaden the patient and carer network we currently engage with to bring in new people and new views including other organisations' patient networks, younger patient groups, groups outside the healthcare and cancer community
- Patient representatives (more than one person) on the organising committee
- Patient/carers co-chairing of more sessions
- A patient prize managed and decided on by patients
- Sessions tailored to patients/led by patients – to include quality of life and patient reported outcome measures (PROMS)
- Learn from other conferences - for example the NCRI Dragon's Den where patients provide researchers with feedback on their work
- Review the bursary application process to help identify where patients and carers may wish to contribute further to the events
- Clearly communicate what patients, carers or the public can expect from the conference to help them better understand how they can use the information and knowledge they gain from attending

- Ensuring accessible information is provided - for example a short lay summary with every poster

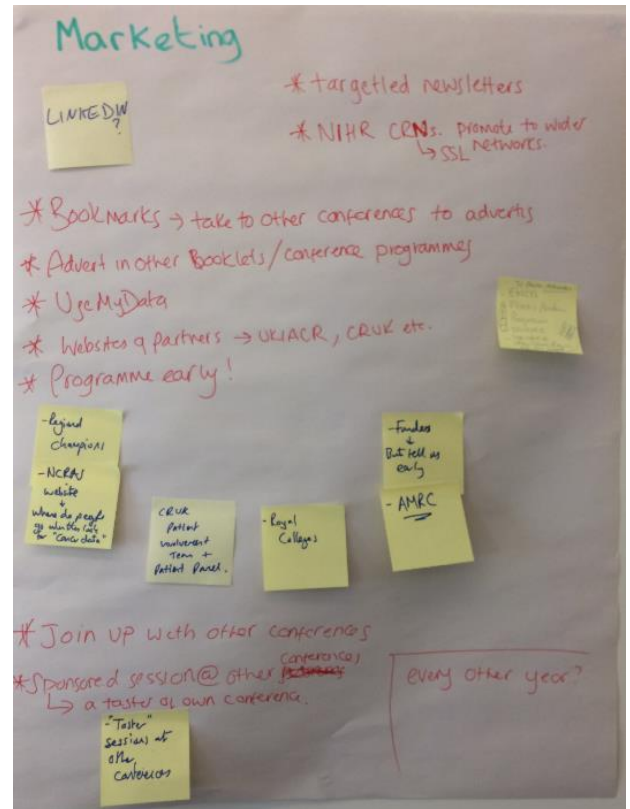


Marketing

Marketing and communications are important to making an event successful. Workshop attendees felt that more could be done to reach new audiences and networks, to ensure key dates and information are communicated effectively and to highlight the value of the event for driving forwards improvements in cancer care and outcomes.

Common suggestions:

- Use 'save the date' notifications as soon as event dates and locations are confirmed
- Provide promotional materials at other industry conferences e.g. NCRI (November), Britain Against Cancer (December), Early Diagnosis Conference (every other February)
- Utilise PHE and partners' social media reach e.g. Twitter updates in the run up to and during the conference
- Where possible encourage media coverage
- Providing taster sessions for the conference at other events
- Creating a post event film to show the key features of the conference
- Ensure the programme and where possible confirmed speaker information is available well in advance so that it can be promoted



Outcomes and next steps

The stakeholder engagement exercise was extremely valuable to us. It enabled us to have detailed conversations about particular aspects of the conference to understand the multiple views and needs of its audience.

We reviewed and analysed the feedback internally and we now have a number of clear actions that we will take forward which we share below. During our 2019 events we will test some of the ideas and suggestions put forward from the workshops which will help inform the changes and content for the conference in 2020.

Continuation of the conference for 2020 and beyond

We are pleased to report that the PHE cancer data conference will continue from 2020.

Additional focused one-day events

This year we have also seen the value of focused one-day events to further engage with the cancer data community and beyond. These events have enabled us to work more closely with partners to discuss and address specific topics and reach new audiences. We will continue to deliver at least 2 one-day events in addition to the conference from 2020, allowing us to provide dedicated coverage of specialties or aspects of cancer data.

Clarify the overall purpose, objectives and themes for the cancer data conference

Many talked about clarifying the purpose and objectives of the conference and so we will develop a refreshed mission statement and set of conference objectives. This will be shared with our stakeholders as part of the conference development process this summer.

The audience

While some stakeholders said we should more clearly define the audience for our events, others said the breadth of the audience that attend the conference is a significant positive point. As cancer data is relevant to many people across the whole cancer community and beyond, it is difficult to define the exact audience and we would not want to exclude anyone from attending. Instead, we will work with specific groups (for example, clinical and local colleagues) who have previously been underrepresented to consider programme content and structure that may appeal more.

Multiple stakeholder working group

In recent years stakeholders have been involved in developing different aspects of the conference, such as abstract scoring and selection, chairing sessions and running individual workshops. Feedback has highlighted the benefits of establishing a single multidisciplinary group to support the development of the conference programme, selection of content and assist in the delivery of the event. We are currently looking at the terms of reference and ways of working for this group.

'So What' factor

We were consistently told that hearing about how data has impacted patient care and outcomes is a vital component of a relevant and well-rounded conference but has often been missing from presentations and posters. We will be taking steps to ensure that the 'So What' factor is covered in all presentations and it will be a condition of the abstract shortlisting process.

A clearer role for patient, carer and public involvement

We will look at ways to reach a wider group of patient, carer and public representatives by working with our partners and stakeholders to link with new networks and engage new voices. There will be a clear role for patients, carers and the public in the development and delivery of the conference including representation on the stakeholder group to help shape the conference, abstract shortlisting and poster prize giving, increased co-chairs for sessions, patient-led sessions and a review of the bursary process.

Develop the networking opportunities

Stakeholders were clear that networking and the collaborations it leads to were some of the most important aspects of the conference. We will look to dedicate more time to networking and to introduce some new approaches to facilitate interactions at the conference.

Wider reach than England

Delegates value the inclusion of presentations and content that covers a wide breadth of geographies and countries. We will work with the UK cancer registries and explore the links with colleagues wider than the UK to ensure the conference programme includes some aspects of international content.

Location and venue

To meet the needs of our delegates and to encourage local representatives to attend, we will explore new locations and venues to host the conference. Ensuring the venues meet our core requirements and are within the PHE policies, we will investigate rotating the conference venue each year.

Enhanced poster sessions

We know people put a lot of the time and effort into producing a conference poster, so we will ensure that sufficient time and space is provided to showcase these. We will consider the needs of the poster exhibitions when looking for new venues and explore ways to dedicate time to poster viewing. For example, via poster networking sessions and more formal poster prize giving.

Improve post event follow-up

Stakeholders told us that post-event follow up was an important aspect of delivering a successful conference and encouraging delegates to act on what they have seen and learned at the conference. It will also help to improve the lasting impact of the conference. We will explore ways to do this including the distribution of presentation slides and the development of post-event materials,

Review of the exhibition stand pricing policy

We would like to encourage as many individuals and organisations to be part of the event exhibition as possible. We have been made aware that our previous exhibition stand pricing policy has inhibited some smaller charities and organisations from taking part. We will therefore review the pricing policy to make it as accessible as possible.

Questions and discussion

We received consistent feedback that delegates value the opportunity to ask questions and hear discussions but that often there is not enough time dedicated to this. We intend to expand the time given throughout the programme for questions and discussion and enable other means for asking questions, such as submitting questions electronically.

Improve marketing and communications

We will take steps to improve marketing and communications in the run up, during and post event. We will take a more targeted approach to reaching specific groups, going beyond our current mailing list to reach new audiences, and enhance the format and timing of releasing the event programme. We will work with colleagues in the Royal Colleges, NHS England, charity and academic networks and the UK cancer registries to do this. We will ensure that any communications we produce are accessible to a patient and public audience and that we clearly communicate the benefits of cancer data. Where possible we will work closely with PHE communications team and our partners and stakeholders to explore ways to increase media coverage before, during and after the conference.

Conclusion

Once again, thank you to everyone who was involved in this process. It has been an invaluable exercise to better understand the importance of the conference for the cancer data community. In taking the time to talk to stakeholders in more detail we can confidently take forward planning for the conference in 2020.

Next steps

The National Disease Registration Service Engagement and Awareness Team will now lead the planning and development of the NCRAS events programme, including the Cancer Data Conference from 2020 onwards.

We will work closely with internal and external stakeholders to address the actions included in this report.

To date we have already started scoping for appropriate venues and we aim to confirm the dates and venue for the 2020 conference by the late summer.

Once all internal approvals and processes have been satisfied we will then communicate with stakeholders about the next steps and opportunities to get involved in the planning and delivery of the conference.

We look forward to seeing you at the Cancer Data Conference in 2020.

For further information about NCRAS conferences and events please contact NDREngagement@phe.gov.uk

Appendix 1

Workshop attendees

Name	Organisation
03/04/2019 London	
Chris Carrigan	use MY data
Chipo Chirewa	Transforming Cancer Services Team for London
Eugenia Lewes	Cancer Research UK
Jane Lyons	Cancer52
Richard Stephens	NCRI Consumer Forum
Alison Stone	use MY data
Kai Winnem	Optimity Advisors
10/04/2019 London AM	
Paul Eves	National Disease Registration Service, PHE
Anna Gavin	Northern Ireland Cancer Registry
Rosie Hinchliffe	Cancer Research UK
Ian Lewis	National Cancer Research Institute (NCRI)
John Marsh	Patient representative
Brendan Moore	National Disease Registration Service, PHE
Andrew Murphy	National Cancer Registration and Analysis Service, PHE
Ruth Swann	National Cancer Registration and Analysis Service, PHE
10/04/2019 London PM	
Julie Flynn	Macmillan Cancer Support
Nicola Keat	National Cancer Research Institute (NCRI)
Robert Kerrison	University College London
Andy Nordin	East Kent Gynaecological Oncology Centre/ National Cancer Registration and Analysis Service Clinical Lead
Richard Roope	Royal College of General Practitioners
David Salisbury	Macmillan Cancer Support
Nannette Spain	Patient representative
Roland Valori	Gloucestershire Hospitals NHS Foundation Trust/ National Cancer Registration and Analysis Service Clinical Lead
17/04/2019 Leeds	
Paul Affleck	University of Leeds
Chris Curtis	The Swallows Head and Neck
Will Jones	brainstrust
Hanhua Lui	National Cancer Registration and Analysis Service, PHE