

A report on NHS Ayrshire & Arran's consultation on Systemic Anti- Cancer Therapy services

October 2023

Acknowledgements

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We would also like to thank the staff at NHS Ayrshire & Arran for the assistance they provided to us in reviewing the engagement process.

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1. Executive summary

This report provides our assessment on whether NHS Ayrshire & Arran has met the requirements and expectations around public engagement set out in [national guidance](#), Planning with People, in its proposal to make permanent the temporary changes introduced to Systemic Anti-Cancer Therapy¹ (SACT) services.

In undertaking our assessment, we have:

- reviewed NHS Ayrshire & Arran's consultation plans and information
- observed at public consultation events
- reviewed local and social media coverage, and
- asked people for their views on the consultation process through an online survey and phone interviews.

As part of their consultation, which took place from 13 February to 19 May 2023, NHS Ayrshire & Arran included a range of online and face-to-face activities and ways for people to ask questions and give their views.

Based on the findings outlined in this report, it is our view that NHS Ayrshire & Arran's process has fully met the Planning with People guidance set out by Scottish Government and COSLA.

The proposal, to make permanent the temporary changes to these services put in place during the COVID-19 pandemic, included:

- Moving Tier 3 SACT delivery from University Hospital Ayr to a refurbished unit on the Ailsa Hospital site. Patients in the University Hospital Ayr catchment to receive their first two cycles of treatment at University Hospital Crosshouse.
- Tier 2 SACT inpatient services and high risk day case treatments moving from University Hospital Ayr and consolidated at University Hospital Crosshouse.

These changes are consistent with the West of Scotland Cancer Network (WoSCAN) model of care for SACT services.

The majority of people who responded to our public questionnaire felt that sufficient information had been given to enable them to understand the proposed changes and why NHS Ayrshire & Arran was considering making these temporary changes permanent. Most respondents felt they had the opportunity to give their views and ask questions, and that it was clear how a decision would be made.

¹ Systemic anti-cancer therapy (SACT) is a collective term for all anti-cancer drug treatments such as chemotherapy and immunotherapy.

In addition, all members of the Stakeholder Reference Group who responded to our questionnaire felt supported to take part in discussions. They felt their comments and feedback were taken into account by NHS Ayrshire & Arran and rated their experience of involvement in this work as 'very good'.

We are aware that some people continue to have concerns regarding parking, transport and travel to University Hospital Crosshouse for the first two SACT cycles and inpatient services.

During this consultation there has not been the same level of political, public or media interest as NHS Ayrshire & Arran's engagement process in 2020 when similar SACT proposals were considered. For example, at that time, a local newspaper launched a public petition to 'Save Station 15 at Ayr Hospital'. There were no public petitions and associated media coverage during this consultation in 2023.

Based on the responses to our surveys, phone interviews and observations and in line with guidance, we have made recommendations to support the points raised during the consultation and to inform NHS Ayrshire & Arran's decision-making, communication of its decision and next steps.

Recommendations for NHS Ayrshire & Arran

1. Actively consider all the views and suggestions of people and communities that have been put forward within the scope of the consultation and use this feedback to help inform the decision-making process. Board members should be open to revisit any previous planning assumptions and consider alternative suggestions that have emerged through the consultation. NHS Ayrshire & Arran should also consider how to respond to feedback and comments received out with the scope of the consultation relating to ongoing service improvement and patient experience.
2. Provide feedback to people on how their views and feedback have been taken into account as part of any recommendations to be submitted to Scottish Government Ministers for final approval.
3. Evaluate the engagement and consultation process, and consider the areas of good practice and learning points.
4. Discuss with Healthcare Improvement Scotland – Community Engagement & System Redesign how we may support any future plans for national, regional or temporary changes to services, to ensure there is meaningful, proportionate and timely engagement with local communities and groups, in line with national guidance.

If the board supports the proposal to make the current temporary changes permanent, we recommend that NHS Ayrshire & Arran:

5. Continue to co-design solutions with people, communities and partners to help mitigate adverse impacts identified through the consultation responses or patient and carer experience, for example, parking and access at University Hospital Crosshouse, increased travel times and transport.

6. Engage people, communities and Third Sector organisations on future developments of SACT services, for example, increasing the number of Tier 3 outreach facilities in other localities.
7. Continue to review and update, as appropriate, the equality impact assessment to ensure there is no disproportionate impact on certain groups or individuals.

With the aim of contributing to continual improvement in the quality of public involvement activities in NHS Scotland, we have identified points which we hope will inform future practice. These are summarised in this report as areas of good practice and learning points.

It is our view, based on the work that NHS Ayrshire and Arran has taken forward, that they have met the requirements and expectations set out in national guidance. This includes making information publicly available, consultation activities and opportunities for people to participate, and the feedback received from participants.

2. Introduction and background

Healthcare Improvement Scotland – Community Engagement & System Redesign² works with NHS boards and Integration Joint Boards to support meaningful engagement with local communities, this includes when they are considering changes to services. We are part of [Healthcare Improvement Scotland](#). We are governed by the [Scottish Health Council](#). You can find out more about how we work to ensure meaningful engagement matters on our [website](#).

The national guidance, '[Planning with People: Community engagement and participation guidance](#)', outlines the process NHS boards and Integration Joint Boards should follow to involve people in decisions about local services. When a proposal is considered to be a 'major service change', we provide external assurance that people and communities have been effectively involved in line with the guidance. For more information on how we quality assure meaningful engagement in line with national guidance, please see [Appendix A](#).

For those service changes that are considered major, ministerial approval on the NHS board's decision is required.

Scottish Government guidance for public engagement and consultation has changed over the duration of NHS Ayrshire & Arran's SACT review. Engagement with people and communities was initially undertaken in line with guidance issued in 2010, outlined in '[Informing, Engaging and Consulting People in Developing Health and Community Care Services](#)'. This was replaced in March 2021 by interim guidance, 'Planning with People', which was in place when the consultation began on 13 February 2023. The interim guidance was reviewed and updated by the Scottish Government and COSLA in April 2023. We have taken these changes in guidance for engagement into account in our assessment.

In 2020, Healthcare Improvement Scotland – Community Engagement & System Redesign gave its view that the initial proposals engaged on by NHS Ayrshire & Arran met the threshold of major service change (see letter in [Appendix B](#)). Proposed changes were:

- Tier 3 SACT services³ would continue to be provided at University Hospital Ayr following initial assessment and the first two SACT treatments at University Hospital Crosshouse

² In August 2023, system redesign was added to Healthcare Improvement Scotland – Community Engagement to build on our work in strategic planning and people led care. We therefore refer to this new arrangement as 'Healthcare Improvement Scotland – Community Engagement & System Redesign' throughout this report.

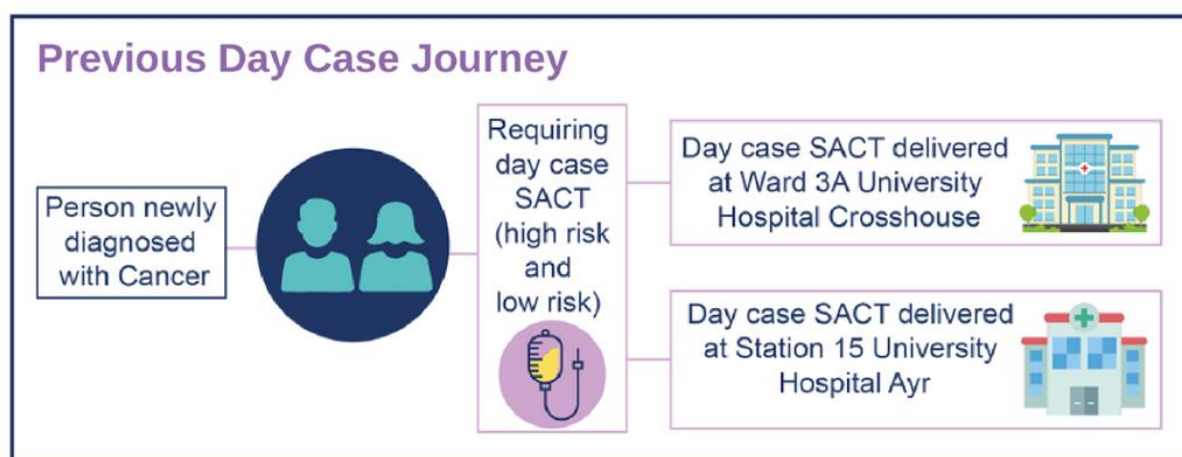
³ Tier 3 SACT services are described as small-medium sized facilities delivering day case treatments to patients assessed and prescribed in a cancer unit/centre. Services would include simple short infusions; subcutaneous (injection in the fatty tissue, just under the skin) treatments; supportive medicines; and be Chemotherapy Specialist Nurse-led delivery. This information is from 'Systemic Anti Cancer Therapy Future Service Strategic Review and Emerging Future Service Model', West of Scotland Cancer Network, 2018, <https://www.woscan.scot.nhs.uk/wp-content/uploads/SACT-Future-Service-Strategic-Review-FOR-WEBSITE-1-v2.0-170418.pdf>

- to consolidate the Tier 2 cancer unit and move eight inpatient Chemotherapy beds from University Hospital Ayr to University Hospital Crosshouse.

However, NHS Ayrshire & Arran was required to make a number of temporary changes to the delivery of the SACT service in response to the COVID-19 pandemic. These temporary changes, which were not subject to consultation at the time⁴, were in line with the proposals they had previously engaged with people on in 2020. In January 2023, NHS Ayrshire & Arran agreed to consult with people on making these temporary changes permanent. The proposal covers day case services (the person receives treatment and leaves the unit on the same day) and inpatients (the person is required to stay in hospital overnight for their treatment and care). The graphics below (developed by NHS Ayrshire & Arran) illustrate how the services have changed from the previous arrangements (in early 2020) to the current/proposed model.

Proposed changes to patient pathway and service delivery for SACT services

Day case



⁴ Engagement and participation in service change and redesign in response to COVID-19, Healthcare Improvement Scotland – Community Engagement & System Redesign, 2021. Available from www.hisengage.scot/service-change/service-change-during-covid-19/

Current / Proposed Day Case Journey

Patient may be assessed for SACT at a face to face appointment or by telephone



Person newly diagnosed with Cancer



Requiring day case SACT



Generally, the first 2 cycles of SACT are delivered at University Hospital Crosshouse when the risk of reaction is highest



Remaining SACT is delivered at University Hospital Crosshouse or Kyle Unit (Ayr) (closest outreach facility to your home address)



Inpatient care

Previous Inpatient Journey

Person newly diagnosed with Cancer



Requiring inpatient SACT (intensive and non intensive)



Inpatient SACT delivered at Ward 3A University Hospital Crosshouse



Inpatient SACT delivered at Station 15 University Hospital Ayr



Current / Proposed Inpatient Journey

Patient may be assessed for SACT in the ward, at a face to face appointment or by telephone



Person newly diagnosed with Cancer



Requiring inpatient SACT (intensive and non intensive)



Inpatient SACT delivered at Ward 3A University Hospital Crosshouse



Background to this service change

Previous service reviews

NHS Ayrshire & Arran has considered a range of service configurations for SACT services over the past ten years. The reasons for these reviews include:

- an increase in the number of patients
- an increase in the volume and complexity of available chemotherapy treatments
- service sustainability, and
- technological developments.

In 2015-16 NHS Ayrshire & Arran undertook an option appraisal for a proposed new model with stakeholders (including patient and public representatives) and prepared a detailed transport impact assessment.

This was superseded in 2017-18 by the WoSCAN, who did a strategic review and developed a regional service model for SACT, based on three distinct tiers of cancer treatment⁵. The board of NHS Ayrshire & Arran endorsed in principle the West of Scotland service model in December 2018 and requested more detailed proposals for future discussion.

The regional service model is described in NHS Ayrshire & Arran's consultation material as:

- Tier 1: Highly specialised treatments that would be delivered in the Beatson Cancer Centre in Glasgow.
- Tier 2: Support for patients with a higher risk of adverse reactions. Patients would normally receive at least two cycles of treatment on an acute hospital site so there is fast access to any medical support that would be needed.
- Tier 3: Support for patients needing lower-risk treatments, which can be delivered with more limited clinical support.

NHS Ayrshire & Arran shows in the diagram below how its proposals to make the current temporary changes permanent would enable the regional 'tiered' SACT service to be developed locally.

⁵ Systemic Anti-Cancer Therapy Future Service Strategic Review and Emerging Future Service Model, West of Scotland Cancer Network, 2018 <https://www.woscan.scot.nhs.uk/regional-work-streams/sact-future-service-delivery-2/>



The regional model was, in part, informed by responses to a patient experience survey (2017) and further engagement activity on this emerging regional model was undertaken (2018) with service users and family members in each of the WoSCAN board areas via six focus groups.

Changes during the COVID-19 pandemic

To help reduce the risk of infection for this vulnerable patient group and staff during the COVID-19 pandemic, a number of changes were made to SACT service delivery at University Hospital Crosshouse and University Hospital Ayr during 2020 and 2021. These included:

- redesigning patient pathways
- moving Tier 3 day case patients from Station 15 in University Hospital Ayr (an acute site) to a fully-refurbished unit at Ailsa Hospital
- consolidating Tier 2 day case and inpatient services at University Hospital Crosshouse
- chemotherapy prescribing units were moved from University Hospital Ayr to the refurbished unit at Ailsa Hospital
- introducing telephone and video appointments, and
- transferring all paper-based patient records onto an electronic system.

Emergency care was not affected by these changes and continued to be provided at the closest hospital for the patient. During these temporary changes, NHS Ayrshire & Arran sought feedback from patients, carers and staff and received over 300 patient responses (from across the day case and inpatient sites) and 84 staff responses. The majority of this feedback was very positive⁶.

NHS Ayrshire & Arran now proposes making these temporary changes permanent. The NHS board asked for patient and public views on these proposed developments and how they might affect people. They also wanted to identify whether there were any further considerations that may still need to be addressed.

NHS Ayrshire & Arran expressed its view that there are aspects of the service model that cannot be influenced through people's participation due to clinical and safety factors, for example location of Tier 2 and inpatient services at University Hospital Crosshouse.

⁶ This information can be found in NHS Ayrshire & Arran's SACT Previous Patient Feedback Summary Report, which is available on their Engagement Hub webpage <https://jointheconversation-nhsaaa.co.uk/sact-public-consultation-2>

Healthcare Improvement Scotland – Community Engagement & System Redesign does not comment on clinical issues. We advised NHS Ayrshire & Arran that if they believed there were any constraints on what could be influenced, this should be clearly explained in the consultation material, with evidence to support this position if required. It should also be clear where people may offer solutions or views on how the service may operate moving forward. This is in line with Planning with People guidance, which states that for consultation “the scope for stakeholder input and influence should be clearly stated”, and

“If there are areas that the engaging organisation believes cannot be influenced, for instance safety, working practices, national policy decisions or budgetary restraints, they must be clearly explained. Any such limitations should be evidenced, and organisations receptive to challenge over scope. It is important to be ready to revisit assumptions or decisions following discussions with the community, or the emergence of new evidence”.

3. NHS Ayrshire & Arran's consultation activities and our findings

In this section we outline what NHS Ayrshire & Arran did to follow the guidance on consulting with people and communities during major service change. We have assessed the consultation process through:

- our observations at NHS Ayrshire & Arran's public drop-in events and online public meeting
- people's feedback via Healthcare Improvement Scotland – Community Engagement & System Redesign's questionnaire and phone interviews
- review of local and social media reviews
- NHS Ayrshire & Arran's consultation material.

NHS Ayrshire & Arran has maintained regular contact with Healthcare Improvement Scotland – Community Engagement & System Redesign throughout, from its initial review of chemotherapy services (2015) to the consultation process. We have provided a visual timeline of NHS Ayrshire & Arran's review of SACT services and engagement with people and communities in [Appendix C](#). More detailed information at each of these stages is provided below.

Engagement

In 2015 NHS Ayrshire & Arran had already started a full review of its chemotherapy services. As part of this review, engagement was undertaken with patients, their families, the wider public and staff to gather their views and feedback on their experiences of the service. Responses were received from across East, North and South Ayrshire.

120 people took part in the survey

- 69.2% of respondents were cancer patients
- 17.5% were patient's family member
- 0.8% were carers
- 5.8% were members of the public
- 1.7% didn't wish to say how they were responding, and
- 5% responded as 'other'

Feedback was taken into account in the development of options for future service delivery. A preferred option was agreed by the Chemotherapy Review Programme Board in September 2015 and NHS Ayrshire & Arran completed a detailed transport impact assessment in 2016.

In 2017-18, the WoSCAN began to develop proposals for a safe, sustainable and high quality SACT service model. As part of this work they developed a Stakeholder Engagement Plan, which included:

- A patient experience survey across all the units delivering SACT in West of Scotland.
- A Stakeholder Reference Group, made up of patients, carers and representatives of cancer charities. Members of the Stakeholder Reference Group offered their perspectives on how to inform and engage with patients, carers and the public on the emerging service model.
- Patient and carer focus groups – six sessions were held across the West of Scotland. These were designed to offer interested people who had used SACT services, and their family members or carers, the opportunity to contribute their views and opinions on the emerging service model.

In 2018 NHS Ayrshire & Arran set up a Patient and Public Reference Group, which included patients who were receiving cancer treatment, or had in the past, and carers. Membership of this group was further refreshed in 2019. Some members, together with Ayrshire Cancer Support, also became core members of the Chemotherapy Review Programme Board, which was re-established in 2018. A representative from Healthcare Improvement Scotland – Community Engagement & System Redesign was also invited to attend to offer advice on the engagement process. The Chemotherapy Review Programme Board considered how the regional service model may be implemented in the board area. As part of this work it considered the criteria from the previous option appraisal (2015) and completed a full equality impact assessment.

In December 2018, the board of NHS Ayrshire & Arran endorsed in principle the West of Scotland service model and noted the need for broad communication and engagement with the public to develop detailed proposals for discussion at a future meeting.

From January to March 2020 NHS Ayrshire & Arran engaged with people and communities on their preferred option, which involved consolidating all inpatient and longer stay infusions (Tier 2) at University Hospital Crosshouse. University Hospital Crosshouse and University Hospital Ayr would provide Tier 3 (lower-risk) treatments to their local catchment populations.

NHS Ayrshire & Arran received 672 responses to its engagement survey on proposals for implementing the regional model. The main themes identified for further consideration were: travel, parking, inpatient beds for chemotherapy and symptom management of end of life care and communication.

Consultation 2023

NHS Ayrshire & Arran carried out a three month public consultation from 13 February to 19 May 2023.

As part of our quality assurance we wanted to know if NHS Ayrshire & Arran was giving people the information they needed, in plain language, to help form a view on making the

temporary changes to SACT services, permanent. We also wanted to know if people had the chance to discuss this information and give their views and feedback.

In October 2022 NHS Ayrshire & Arran set up a Stakeholder Reference Group with patients and carers from across East, North and South Ayrshire to help plan the consultation and review the public information to ensure it was written in plain language and clearly laid out. They also provided feedback on the draft equality impact assessments.

Members of the previous Public Reference Group, involved in the 2020 engagement process, were invited to take part in the Stakeholder Reference Group, with ten people registering their interest in joining. A range of approaches were used to recruit more people to the Stakeholder Reference Group, including invitation via the Ayrshire Cancer Forum at its meeting in October 2022 (attended by members of local cancer groups), posters in hospitals and community settings, and plans to hold two public sessions on the opportunity to be involved, promoted via social media. Unfortunately there were no further expressions of interest received.

Healthcare Improvement Scotland – Community Engagement & System Redesign attended two meetings of the Stakeholder Reference Group at Kyle Unit, Ayr and met with NHS Ayrshire & Arran’s engagement team to provide advice and share good practice.

As part of our assessment we prepared and sent a questionnaire to members of the Stakeholder Reference Group to reflect their work in supporting NHS Ayrshire & Arran in planning the consultation process. This could be completed online or by phone. We received five responses to our questionnaire from the Stakeholder Reference Group.

All information relating to the consultation was contained on a dedicated webpage (also referenced as the Join the Conversation [Engagement Hub](#)):

- Consultation summary document
- Survey links (online and downloadable copy)
- Frequently asked questions
- Patient feedback on the changes that were initially put in place on a temporary basis
- Equality impacts assessments for the proposal and process – these were kept ‘live’ so they could be updated to reflect people’s feedback to the consultation
- Background and supporting information
- Details on how to get involved

The Engagement Hub webpage had a number of interactive features, which included a poll for people to say how they had heard about the proposals, ‘ask a question’ and ‘tell a story’.

NHS Ayrshire & Arran offered to provide, on request, information in an easy read version or in alternative languages or formats. They offered people assistance, if required, to respond to the consultation. Information on the proposal was sent to targeted groups and contacts, for

example the Pan Ayrshire Equalities Group, Gypsy/Traveller Integration and Engagement Officer, Chinese Community Association and local housing teams.

A snapshot of NHS Ayrshire & Arran's consultation activity can be found in [Appendix D](#).

The table below outlines some of NHS Ayrshire & Arran's activity to raise awareness and engage with people during the consultation and what Healthcare Improvement Scotland – Community Engagement & System Redesign did to assess this activity.

What NHS Ayrshire & Arran did to raise awareness of the consultation and engage with people and communities	What Healthcare Improvement Scotland – Community Engagement & System Redesign did as part of our assessment
Prepared a consultation plan and dissemination list which detailed who would receive consultation material and in which format.	Reviewed NHS Ayrshire & Arran's draft consultation plan and dissemination list and provided comment.
Seven press releases were issued to local and national media outlets at the start of the consultation and at key points during the three month consultation period	Reviewed local press coverage for published articles, discussions or issues raised.
Community briefing papers were sent to all community contacts, including community councils, councillors, elected members, GPs, pharmacies, dental practices, and partnership agencies	We emailed information about the consultation and our quality assurance questionnaire to MSPs (10), MPs (4), councillors (93), community councils (40 directly and 22 via a central mailing address) and community groups (13) – a reminder was sent four weeks after the initial email.
Direct mailing to key community contacts, for example, local cancer charities and people who had signed up to databases	
Briefing and consultation materials were sent to Health and Social Care Partnership chief officers/ Integration Joint Boards' and local authorities' communications teams	We wrote to Health and Social Care Partnerships, locality and engagement groups and asked them to disseminate our questionnaire to their networks.
Social media activity throughout the process e.g. Twitter and Facebook, to encourage people to provide their views and raise awareness of updates	Reviewed social media coverage for articles, discussions or issues raised.
Posters, the consultation document and paper copies of the survey were sent to	We looked out for visibility of the consultation in some public areas, for

public libraries, health and care facilities, and community settings	example public libraries, health and care facilities.
Printed information was made available at public drop-in events, sent to public libraries and an offer was made to provide this to people on request.	We saw consultation information in more than half the venues we visited.
Three public drop-in events to share information and gather people's views at the Corn Exchange, Ayr; Fullerton ConneXions, Irvine; and, Ayrshire Cancer Support, Kilmarnock (daytime)	We observed at the three public drop-in events in Ayr, Irvine and Kilmarnock.
An online public meeting (evening)	We observed at the online public meeting and posted a link to our questionnaire in the 'chat box'.
Staff briefing issued with updates on the programme and informing about engagement events	The effectiveness of an organisation's engagement with its own staff is beyond our scope for comment or assessment.
Responded to requests for additional meetings: • Girvan and South Carrick Villages Locality Planning Partnerships, and • Troon and Villages Locality Planning Partnership	We did not attend the additional meetings that were scheduled on request from local groups. However, one person who took part in our phone interview commented: "I knew they (NHS Ayrshire & Arran) would come to locality and community meetings if invited and that they were having the public events".
Engaged with the local Third Sector interface and local community groups to support people's inclusion in the consultation (for example, Ayrshire Deaf Club)	NHS Ayrshire & Arran received feedback via the online Engagement Hub from a person with a sensory impairment. A focus group was subsequently arranged with the Ayrshire Deaf Club, supported by an additional BSL interpreter, and 16 group members attended.
Online and paper surveys (one general and one for patients who were accessing SACT treatments).	We developed a quality assurance questionnaire for Healthcare Improvement Scotland – Community Engagement & System Redesign seeking people's feedback on their experience of being involved in the

	consultation process. We received a total of 12 full responses. We prepared posters and postcards to help promote our questionnaire (with a web link and QR code) and these were made available at the public drop-in events and NHS Ayrshire & Arran agreed to make these available in SACT patient areas. A post to raise awareness of the survey was put on our webpage and NHS Ayrshire & Arran's online Engagement Hub webpage.
Freephone number and dedicated email address for people to request paper copies of the consultation material or support in completing the survey	Healthcare Improvement Scotland – Community Engagement & System Redesign questionnaires could be completed online, emailed or sent to our Freepost address.

What we found

- Local, voluntary and community groups, for example, Ayrshire Cancer Support, Voluntary Action South Ayrshire, The Ayrshire Community Trust, and some community councils used social media to raise awareness of the consultation and encourage people to be involved.
- Partnership public bodies communicated information about the consultation via their social media networks, for example East, North and South Ayrshire Health and Social Care Partnerships, North Ayrshire Community Planning Partnership.
- NHS Ayrshire & Arran used different visuals and approaches on social media posts to provide information on the consultation, sustain interest and encourage people to get involved through different methods.
- There was local media coverage, including Ayrshire Live (Daily Record), Irvine Times, Ayr Advertiser, Cumnock Chronicle, Ardrossan Herald and West FM/Planet Radio. Media coverage tended to be neutral in tone and content.
- Posters and information were displayed in some public libraries, for example, Troon, Prestwick, Forehill Branch Library (Ayr), Carnegie Library and the Dick Institute. We also saw posters in acute and primary health settings including University Hospital Ayr, University Hospital Crosshouse and Station Road Medical Centre, Prestwick. Some practices uploaded information about the consultation onto their websites, for example, Dalry Medical Practice.
- Public attendance at the drop-in events ranged from 47 attendees at the Corn Exchange in Ayr (36 people actively engaged in discussions on the consultation), to two people at

Ayrshire Cancer Support, Kilmarnock and no attendees at Fullerton ConneXions, Irvine. The venues selected for the public drop-in events were central and accessible.

- Eight members of the public and six staff attended the online public meeting, where a presentation on the proposal was given by the Macmillan Nurse Specialist and Clinical Director Cancer, and people were invited to ask questions and share their views. A copy of the presentation was emailed to attendees after the meeting. From our observations, NHS Ayrshire & Arran staff responded in a constructive and supportive manner to all questions and comments from attendees.
- NHS Ayrshire & Arran received a total of 410 responses to the public consultation. This included 190 responses from current service users on their experience of the Tier 2 and Tier 3 pathways, environment and access. There were 166 responses from members of the public and 54 from staff members.

What people told us

a. Stakeholder Reference Group questionnaire

We received feedback (online and by phone) from five members of the Stakeholder Reference Group. We understand that 10 people registered an interest in joining the Stakeholder Reference Group and so this represents a 50% response rate. All members of the Stakeholder Reference Group who responded to our questionnaire felt supported to take part in discussions. They said they had enough time to read and comment on draft information, for example, survey questions. They also felt their comments and feedback were taken into account by NHS Ayrshire & Arran.

All respondents felt their involvement in the Stakeholder Reference Group had genuinely helped to shape the consultation and rated their experience of involvement in this work as 'very good'. In terms of planning the consultation they all agreed they had been given the opportunity to:

- consider and identify who may have an interest in or be affected by the proposal
- influence the range of methods and tools used for engagement, for example, questionnaires, meetings, social media
- contribute to the impact assessment to ensure the consultation process was inclusive and accessible

Generally, people felt the membership on the Stakeholder Reference Group was appropriate, however some members noted:

- there weren't many young people
- it wasn't ethnically diverse
- more recognition that others, in addition to the patient and clinical staff, are involved in cancer care.

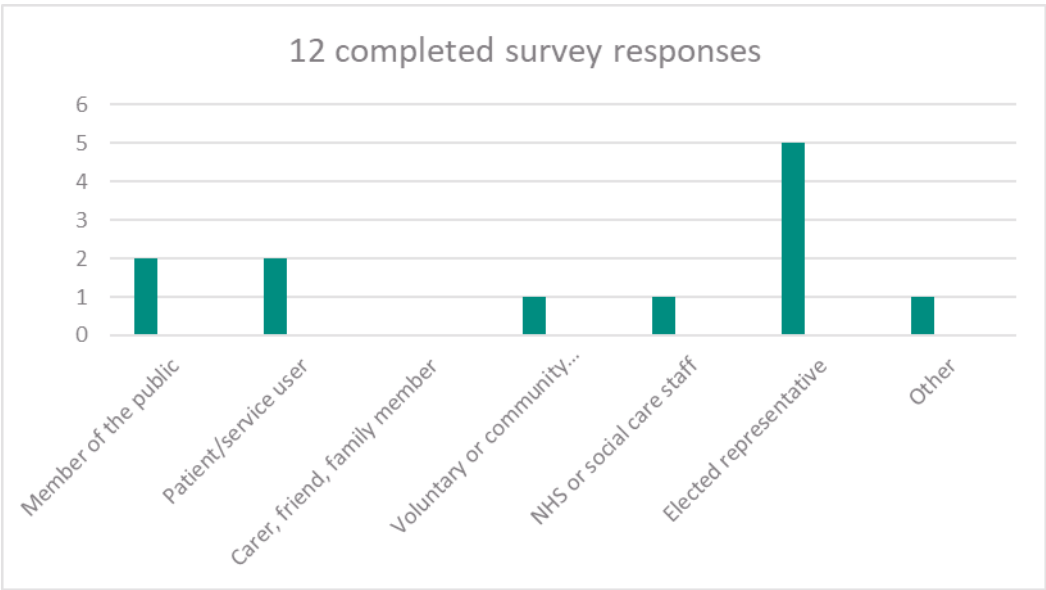
Some comments from the Stakeholder Reference Group members

“Almost a whole meeting was devoted to the ways people could be reached to learn about the proposals. No suggestion was ignored.”

“The group looked at how the proposals could be known through Ayrshire and Arran. That done, extensive thought in groups, and community organisations were identified to provide information and planned meetings were also agreed to provide chance for people to come and talk about the proposals.”

b. Public questionnaire

We received a total of 12 fully completed questionnaires. We also received 11 partially completed questionnaires, four of which did not contain any data. Seven of the partially completed questionnaires included varying degrees of data, including postcodes, which showed a level of awareness of our questionnaire across the three local authority areas. Our findings outlined in this report are based on the 12 fully completed questionnaires.



We acknowledge the low response rate to our questionnaire. This may be, in part, an indication that NHS Ayrshire & Arran has given people and communities the information and opportunities they need to be involved in the consultation. The findings from our questionnaire, outlined in this report, are in line with our observations at NHS Ayrshire & Arran’s drop-in events and public meeting, which support the validity of our findings. Looking at our findings alongside feedback that NHS Ayrshire & Arran received to equivalent questions in their consultation survey, for example on clarity of information on why changes were made during the COVID-19 pandemic, how the regional ‘tiered’ model was developed locally and the consultation proposal, responses are similar and support our findings.

All 12 respondents felt that the consultation document gave them enough information to understand the proposed changes and eight of them had completed NHS Ayrshire & Arran's consultation survey. One person commented that the language could have been simpler, for example, describing this as "a consultation on local chemotherapy services" rather than SACT services.

Eleven respondents felt that NHS Ayrshire & Arran had clearly explained how the proposal had been developed from the regional 'tiered' model and how a decision on whether to make the temporary changes permanent will be made. Nine people felt that the reasons for considering making the temporary arrangement permanent were clearly explained. Eleven respondents felt they had the opportunity to give their views on the proposal and the majority (eight) felt they had the opportunity to ask questions.

Five people felt their views were listened to, with two people feeling their views were not listened to and four people being unsure. Six people felt their questions were answered, with one person feeling their questions were not answered and four people being unsure. When asked to 'tell us why you feel this way' in responding to the latter two questions, we received further information from four of the 12 respondents. One person who responded 'no' to both questions felt that "NHS Ayrshire & Arran is determined to do their own thing and the consultation is a box ticking exercise only". One person who responded 'yes' to both questions felt that "the service is always thorough" and two people who responded 'unsure' noted "I didn't submit any views or ask any questions" and "not applicable".

The infographic below illustrates some of the key findings from the 12 fully completed questionnaires.

What people told us...

12

responses to our
questionnaire



3

top ways people
heard about the
consultation

1. community council/local group
2. email from partners/networks
3. received information from NHS Ayrshire and Arran

Feedback to our survey

12

felt enough information was
given to understand the
proposed change

11

felt they had the opportunity
to give their views

9

felt the reasons for making the
temporary changes permanent were
clearly explained

8

felt they had the opportunity
to ask questions

11

felt that how the proposal has been
developed from the regional model was
clearly explained

11

felt that how a decision will be
made was clearly explained

What people told us...

Comments we received from people included the following:



It is difficult to appreciate the impact that these changes will have, not having had personal (or close family/friend) experience with the service. Hopefully the people who required these services will respond with their views.



I chose not to respond to the consultation at this time.



Consider how to make the changes more relatable to people. Bring everything back to the level and way people live.



I feel this consultation is a complete waste of time as NHS A&A have already made its mind up.



c. Phone interviews

We asked people who completed our questionnaire if they would be willing to take part in a phone interview to provide more information. Four of the six people who originally indicated they would be willing to take part, participated in a phone interview at the end of May and June.

Generally, participants felt the consultation had been well publicised. There was recognition that, following the COVID-19 pandemic, there may be lesser public footfall in some areas, for example, GP surgeries. One person felt that, while social media may reach large numbers of people, it may not be helpful in providing a balanced view or be accessible to some

communities, for example, “a generation thing”. An observation was made on how social media is used, and the need to break information down into smaller ‘chunks’ to make it accessible to people. There was also a concern that some people may be ‘missed’, for example, those who don’t typically engage with health services and refugees whose first language isn’t English. One person was “mindful that everyone reads everything in a different way. Feel it was good information included visuals”.

People suggested the methods of engagement be evaluated to consider how effective these had been. There was support for both online and in-person engagement to build relationships, and share the most current information. Some quotes from participants are given below:

“By and large the consultation meeting was well organised and it’s hard to see how it could be run any better.”

“Look carefully at the language in communications and letters; use of jargon and ‘customer’ friendly.”

“Generally things develop over time and changes in treatments mean that services will need to change. People’s information can become ‘old hat’ so to speak, and it’s important to bring people and services up-to-date.”

“Continue to assess the service and listen to what patients are saying. They are the most affected.”

“What [NHS Ayrshire & Arran] have been doing is good and carry on in the same vein.”

4. Conclusions

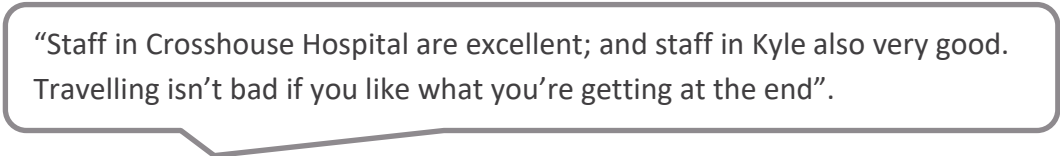
Based on the findings in this report, Healthcare Improvement Scotland – Community Engagement & System Redesign confirms that NHS Ayrshire & Arran’s engagement and consultation on proposals for SACT delivery has met the national guidance set out by the Scottish Government and COSLA.

The majority of the feedback we collected was positive about the consultation process, which is in agreement with our observations and review of the materials and activities developed. When questions and concerns were raised by patients and members of the public at public events, these were actively listened to by NHS Ayrshire & Arran and appropriately responded to.

From our observations and the feedback received through our activity outlined in the section above, NHS Ayrshire & Arran has clearly explained to people and communities the changes, how they were developed and why it was considering making the current temporary changes permanent.

We feel that NHS Ayrshire & Arran has taken an open and transparent approach to sharing information with people and communities on its Engagement Hub webpage. We also note the approach they took to encourage some interaction with visitors to the Engagement Hub, for example, features to complete a poll (66 people responded to a question on how they found out about the SACT consultation, with 64% saying from social media), ‘ask a question’ and ‘tell a story’ sections.

NHS Ayrshire & Arran has carefully considered the feedback it received from its engagement activity in early 2020 to further develop proposals. At that time, concerns were raised around increased travel times, transport and access. Patient pathways have since been further developed to ensure that, where clinically safe, people can be treated as close to home as possible. At the online public meeting, one participant commented they had attended cancer services for a long time, and:



“Staff in Crosshouse Hospital are excellent; and staff in Kyle also very good. Travelling isn’t bad if you like what you’re getting at the end”.

In addition, in response to concerns raised in the feedback to the 2020 engagement on how information would be shared across the two hospital sites, a new ‘paper lite’ system (where all paper-based patient records was transferred onto an electronic system) was set up – meaning that information is now more securely and speedily accessed by staff.

People’s feedback to the 2020 engagement activity highlighted concerns that Station 15 at University Hospital Ayr may close – this was not part of the plans at that time. However,

measures put in place in response to the COVID-19 pandemic, meant that, to ensure safe treatment and care for these clinically vulnerable patients, SACT delivery was temporarily moved from Station 15 to the newly refurbished Kyle Unit on the Ailsa Hospital site. This was explained in the consultation material and at the online public event and the move was supported by those patients present.

From our observations at the Stakeholder Reference Group meetings, the public drop-in events and the online public meeting, NHS Ayrshire & Arran staff encouraged people to participate by listening to and responding fully to questions, for example, repeating questions to ensure shared understanding and then checking-back that the person was satisfied with the response before moving on.

We support NHS Ayrshire & Arran's approach to using both digital and face-to-face methods to share information and engage with people. However, while a variety of methods and media were used to promote the consultation, we are aware, from our attendance at the online public meeting and public drop-in events, that attendance was fairly low. Similarly, the number of responses to NHS Ayrshire & Arran's consultation survey is lower than that received to the engagement in 2020 i.e. 672 responses compared with 420 responses (2023). This may have been influenced by a number of factors:

- The temporary model has been in place for over two years and people (patients and staff from the Kyle Unit, Ayr and University Hospital Crosshouse) have provided mainly positive feedback on their experiences.
- Feedback from the engagement activity (January – March 2020) has been considered in the temporary arrangements put in place. For example, in response to concerns about increased travel times, patient pathways have been redesigned and the introduction of phone consultations (where clinically safe) has helped reduce travel for many patients. There has also been increased Tier 3 SACT activity at University Hospital Ayr.
- Local and social media coverage has been more focussed on reporting on the proposal itself, with elected representatives encouraging people to take part in the consultation. We are unaware of any opposing opinions to the model being expressed by elected representatives.

This is the first public consultation for a major service change in Scotland since the COVID-19 pandemic and, while the core principles of engagement remain the same, there is inevitable learning and changes in practice for public bodies, people and communities on how participation will look moving forward. People who took part in our phone interviews felt the use of social media should be used alongside other methods to ensure the process was inclusive for all. They also felt that, while information may be available to the wider community, people may not be sufficiently aware of, or motivated to participate, if they do not feel the changes affect them directly. Therefore, it is important to consider how to make the information and language more relatable.

In line with the guidance, NHS Ayrshire & Arran undertook ongoing evaluation of its consultation process, and this included a mid-term review with input from Healthcare

Improvement Scotland – Community Engagement & System Redesign and the Stakeholder Reference Group. This enabled them to consider the responses to their consultation and interactions and identify any improvements that could be made during the process. For example, they updated the Frequently Asked Questions document, reviewed visibility of documents on the online Engagement Hub and reviewed the survey responses to target some proactive posts.

The engagement undertaken in early 2020 highlighted initial patient and public concern and a lack of public assurance about aspects of the proposed changes to SACT services. As has been suggested above, the temporary arrangements have been helpful in providing patients, staff and the public with a better understanding of the changes and their impacts.

NHS Ayrshire & Arran should note the changes in the updated Planning with People guidance in relation to expectations of engagement in relation to temporary and regional changes for future service review.

5. Areas of good practice and learning points

With the aim of contributing to continual improvement in the quality of public involvement activities in the NHS in Scotland, we have identified the following points which we hope will inform future practice. These are summarised as areas of good practice and learning points.

Areas of good practice identified by Healthcare Improvement Scotland – Community Engagement & System Redesign

- We feel the process has benefited from the way in which NHS Ayrshire & Arran has clearly described how people's feedback at each stage in the process has helped to inform the next. For example, the Chemotherapy Review Programme Board considered the criteria used from the previous option appraisal to inform its preferred option. Feedback from the 2020 engagement was considered in the development of the temporary service model.
- The consistent involvement of clinical leads in the engagement and consultation process and at public (face-to-face and online) and community events to fully respond to people's questions and provide assurance.
- As well as providing information online and using face-to-face methods, NHS Ayrshire & Arran has started to develop interactive methods of dialogue with people and communities via its Engagement Hub webpage e.g. ask a question, complete a poll.
- NHS Ayrshire & Arran successfully used a range of graphics in its social media postings to convey different information about the service and to actively encourage people to participate in the consultation.
- The range of activities undertaken to make people aware of the opportunity to self-nominate to take part in the Stakeholder Reference Group demonstrates genuine openness to work with a range of people.
- The use of diagrams to supplement the consultation information, illustrating the differences between the previous and current/proposed patient journeys, was helpful and supported clarity and understanding.
- NHS Ayrshire & Arran has been proactive in responding to requests to attend local meetings.

Learning points identified by Healthcare Improvement Scotland – Community Engagement for future processes

- As well as providing people with the opportunity to self-nominate to take part on Stakeholder Reference Groups or planning groups, consider whether membership may also benefit by targeting representatives from other parts of the patient journey, communities (geographic or interest) or the Third Sector.
- Consider how information and communications can be made more direct and relatable to people, to encourage greater awareness and participation, through the use of more common language.
- Given the increasing use of digital communication, continue to evaluate digital and face-to-face methods to gauge their effectiveness in information sharing, building relationships and trust with communities, and supporting 'live' dialogue. In particular, ensure methods (both digital and traditional) support engagement with people with different communication needs and preferences and from diverse backgrounds.

6. Recommendations

We have made the following recommendations to support the points raised during the consultation and to inform decision-making, communication of any decision and next steps.

Recommendations for NHS Ayrshire & Arran

1. Actively consider all the views and suggestions of people and communities that have been put forward within the scope of the consultation and use this feedback to help inform the decision-making process. Board members should be open to revisit any previous planning assumptions and consider alternative suggestions that have emerged through the consultation. NHS Ayrshire & Arran should also consider how to respond to feedback and comments received out with the scope of the consultation relating to ongoing service improvement and patient experience.
2. Provide feedback to people on how their views and feedback have been taken into account as part of any recommendations to be submitted to Scottish Government Ministers for final approval.
3. Evaluate the engagement and consultation process, and consider the areas of good practice and learning points.
4. Discuss with Healthcare Improvement Scotland – Community Engagement & System Redesign how we may support any future plans for national, regional or temporary changes to services, to ensure there is meaningful, proportionate and timely engagement with local communities and groups, in line with updated national guidance.

If the board supports the recommendation to make the current temporary changes permanent, we recommend that NHS Ayrshire & Arran:

5. Continue to co-design solutions with people, communities and partners to help mitigate any adverse impacts identified through the consultation responses or patient and carer experience, for example parking and access at University Hospital Crosshouse, increased travel times and transport.
6. Engage people, communities and Third Sector organisations on future developments of SACT services, for example increasing the number of Tier 3 outreach facilities in other localities.
7. Continue to review and update, as appropriate, the equality impact assessment to ensure there is no disproportionate impact on certain groups or individuals.

Appendix A

The table below shows how we quality assure meaningful engagement in line with national guidance, Planning with People.

Identifying the issue (need for change), stakeholders and planning communication and engagement
Planning: • Develop information detailing the rationale for change, any known timescales, the reasons for engagement and shared understanding of objectives. • Develop an Equality Impact Assessment (EQIA) of the engagement and consider whether a Fairer Scotland Duty assessment may be appropriate. • Identify stakeholders and establish an engagement planning team. Involve community representatives at the earliest stage to oversee process for service change. • Evaluation of engagement activity should be continuous. • Work collaboratively with partner organisations to draw on existing collective knowledge, experience and infrastructures to support community engagement. Information: • Share information with stakeholders who may potentially be affected by any change proposal. • Ensure access to accurate information in order to engage effectively. • Be clear if there are areas that cannot be influenced, for example, safety, working practices or budgetary restraints, and explain and provide evidence of this (if requested). • Provide regular updates and feedback to participants as part of the engagement activity. All information should be co-produced, presented clearly and made widely available.
Engage with those potentially affected (engagement) and evaluation
Planning: • Identify the best approaches to reach the people whose views need to be shared and heard. • Be open to hearing new ideas and understand all the issues for communities. Engage with those potentially affected: • Routinely assess the impact of engagement activity to ensure the right people are being involved, and their experience is monitored.

- Local people should be involved in developing options to be taken forward that are robust, evidence-based and person-centred.
- Undertake EQIA of policy or service redesign proposals.
- Be ready to revisit assumptions or decisions following discussions with the community, or the emergence of new evidence.

Engage with those potentially affected (consultation) and evaluation

Specific considerations for public consultations:

- No final decision must have been reached.
- The information provided must relate to the consultation and must be available, accessible and easy to interpret to enable affected people to provide an informed response.
- There must be sufficient time and opportunity for affected people to participate.
- Decision-makers must be able to provide evidence that they took consultation responses into account.

Specific considerations for major service change:

- Proposals for major service change must be subject to at least three months of public consultation and, ultimately, Ministerial approval.

Decision-making and feedback

Feedback:

- Keeping participants informed about the progress of engagement is an important part of the process and should take place throughout.

Appendix B

Letter from Healthcare Improvement Scotland – Community Engagement & System Redesign to NHS Ayrshire & Arran on its engagement process, 12 May 2020.



Healthcare
Improvement
Scotland

Community
Engagement

Glasgow office

Delta House

50 West Nile Street
Glasgow

Date: 12/05/2020

Professor Hazel Borland
Nurse Director
Interim Deputy Chief Executive
NHS Ayrshire and Arran,
Eglinton House,
Ailsa Hospital
Dalmellington Road,
Ayr
KA6 6AB

Dear Hazel

NHS Ayrshire & Arran – Chemotherapy Services Review

Thank you for submitting information on proposed changes to chemotherapy services in NHS Ayrshire & Arran.

Healthcare Improvement Scotland – Community Engagement recognises that this proposal has been developed from the emerging West of Scotland Cancer Network tiered model. It is our understanding that proposed changes to regional or national services should follow the principles set out in the Scottish Government's guidance, CEL4 (2010)¹.

As part of the regional model, Tier 1 services will be provided at the Beatson Cancer Centre in Glasgow, with NHS Ayrshire & Arran's proposed change including the provision of:

- The Tier 2 cancer unit at University Hospital Crosshouse (also serving as an outreach facility for its local catchment area)
- Tier 3 outreach facility provided at University Hospital Ayr
- Eight inpatient chemotherapy beds transferred from University Hospital Ayr and consolidated at University Hospital Crosshouse
- Some specialist services and treatments may be repatriated from the Tier 1 regional cancer centre (in Glasgow) to NHS Ayrshire & Arran.

This proposal would mean that all patients currently attending University Hospital Ayr would go to University Hospital Crosshouse for their initial assessment and first chemotherapy treatment.

¹ https://www.sehd.scot.nhs.uk/mels/CEL2010_04.pdf

Following the initial assessment and treatment, it is anticipated that around 75% of treatments would continue to be delivered from University Hospital Ayr for those patients that would currently access their care there.

View on status of proposal

Based on the information you have shared with us, we have considered whether this proposed change would likely meet the general threshold for 'major service change'.

We feel the proposal meets the threshold for major service change on the basis that:

- Patients who are already vulnerable due to their illness may have to travel further for the initial assessment and first treatment, with a proportion also requiring to do this for further treatment appointments.
- It is unclear from the information available how many people currently attend University Hospital Ayr for their first consultant assessment appointment and first treatment.
- There has been significant public and political interest to the proposed changes with two online petitions (attracting over 13,900 signatories) – The Ayrshire Post, 'Save Station 15 at Ayr Hospital'² and a local councillor petition 'Save Station 15 – Retention of services in Station 15 Ayr Hospital'³
- Proposed change will support the implementation of the emerging West of Scotland tiered model. We are aware that engagement with some service users and carers took place early in the process. However, it is unclear to *Healthcare Improvement Scotland – Community Engagement* how information on this emerging regional model has been made publicly available and what further opportunities people and communities have had to provide their views on it.

In our considerations, we note that NHS Ayrshire & Arran refers to existing operational challenges and potential benefits of the proposal, which include enhanced safety, sustainability of the service and access for patients.

Next steps

We believe that the engagement activities undertaken to date, the increased level of public awareness and the feedback received from patients and the public will be valuable in moving forward to consultation. The public consultation should meet the requirements as set out in CEL 4 (2010) guidance.

The engagement undertaken by NHS Ayrshire & Arran from January to March 2020 included focus groups, public information, discussions with patients and carers in clinical settings, local media coverage and an engagement survey. In particular, the *Community Engagement Directorate* highlights the significant number of people who were made aware of the proposal through the range of approaches used by NHS Ayrshire & Arran. In addition, the engagement survey achieved a good return of 671 responses from geographic areas across NHS Ayrshire & Arran with 69% of respondents being members of the public or patients. The feedback from this exercise has enabled you to identify a number of themes that people felt required further consideration, including:

- Additional travel times for some patients and parking challenges
- Poor public transport links, rurality and increased cost of travel

² <https://www.change.org/p/jeane-freeman-msp-ayrshire-post-save-station-15-at-ayr-hospital> (29.04.20)

³ <https://www.change.org/p/nhs-ayrshire-and-arran-retention-of-services-in-station-15-ayr-hospital> (29.04.20)

- Consolidation of inpatient beds for chemotherapy and symptom management/end of life care
- Relationships with clinical and nursing staff and continuity of care

The consultation offers an opportunity to further understand the concerns and issues that people have raised so far and what considerations could be taken to respond to these points. With transport and access identified by approximately 70% of the 671 respondents, a focus of the engagement during this consultation should be targeted to understand what the concerns are from the geographic areas; what potential mitigating steps are possible; and, how these could potentially be delivered in any future model.

We are aware that some people did not appear to fully understand the proposals when made public, with perceptions that Station 15 at University Hospital Ayr may close. The consultation materials will offer an opportunity to further articulate the reasons for change and describe the proposed model. We are aware that some materials were produced in the latter parts of the recent engagement to support these. It will be important to use this type of material and build on it.

In proceeding to public consultation, NHS Ayrshire & Arran should clearly articulate which aspects of the Chemotherapy Services Review proposal people can influence through their involvement and where there are constraints that may limit choice, ensure the reasons for this are shared. For example, if the West of Scotland regional model places constraints on how chemotherapy services may be delivered within NHS Ayrshire & Arran, this should be clearly explained. However, the Board should be informed of, and give genuine consideration, to any alternative suggestions that are put forward as a result of the consultation.

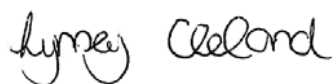
The priority and focus of both the public and the NHS is currently in responding to the COVID-19 pandemic and we recommend careful consideration be given to the most appropriate time to take this consultation forward. We would welcome the opportunity to discuss the practicalities of this with you.

If the proposal changes I would ask that you contact us at the earliest opportunity as it may be necessary to review this position.

Whilst the points raised represent the view of *Healthcare Improvement Scotland – Community Engagement*, the decision on whether a change to services should be designated as 'major' rests with the Scottish Government.

Please contact me if you wish to clarify any of the above points.

Yours sincerely

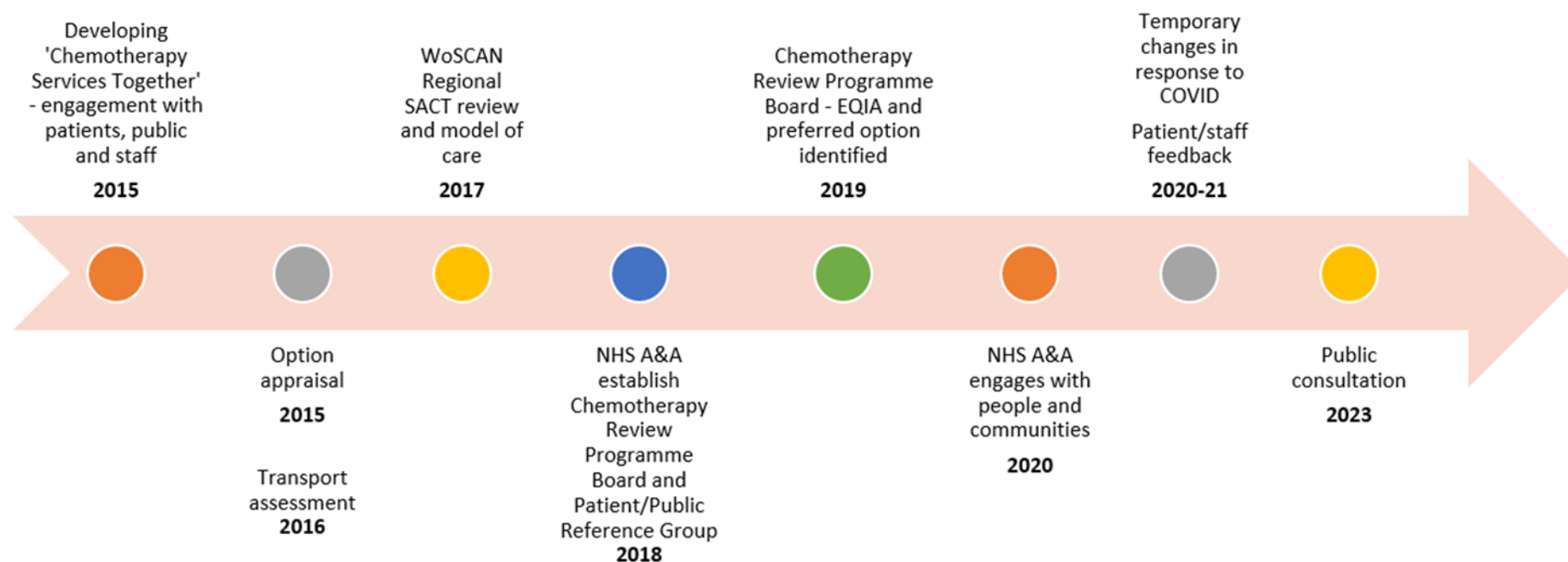


Lynsey Cleland
Director of Community
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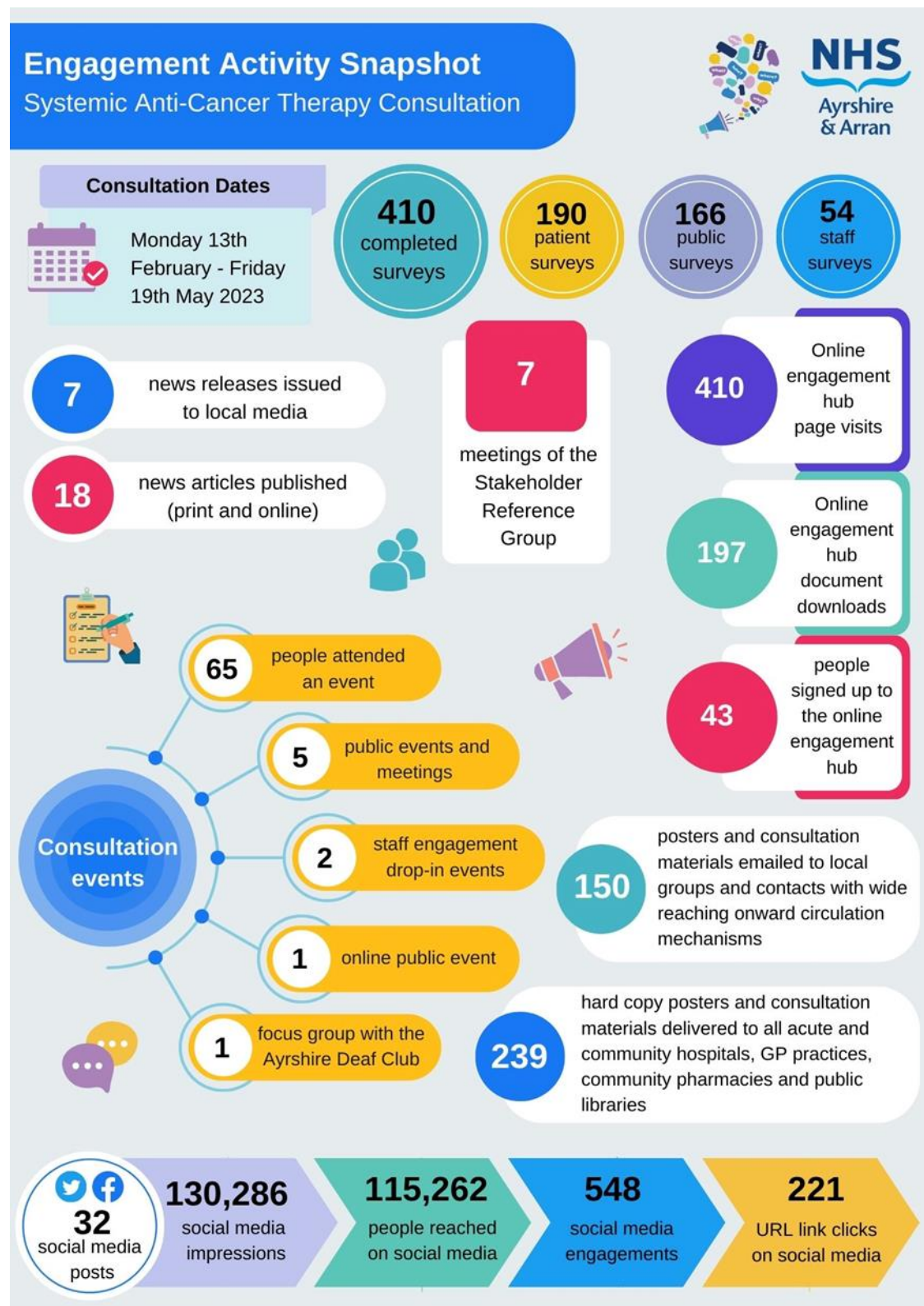
Appendix C

The timeline for the review and development of proposals for SACT services in NHS Ayrshire & Arran



Appendix D

NHS Ayrshire & Arran's snapshot of the consultation activity it has done from 13 February to 19 May 2023



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You can read and download this document from our website.

We are happy to consider requests for other languages or formats.

Please contact our Equality and Diversity Advisor on 0141 225 6999

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