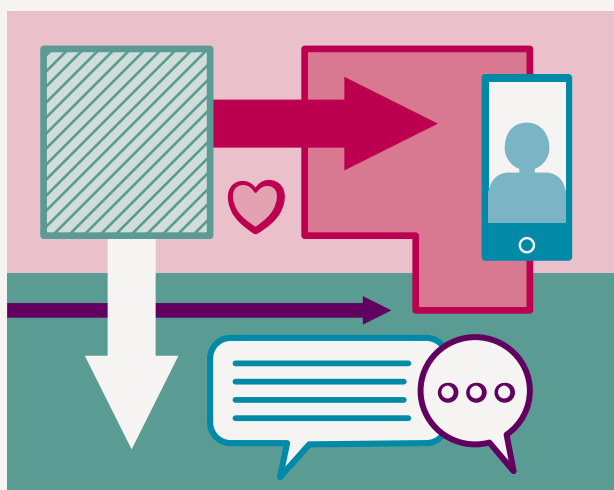


Health and Social Care Alliance Scotland (the ALLIANCE)

Organ transplant focus groups –

Integration, Engagement
and Lived Experience Hub



August 22

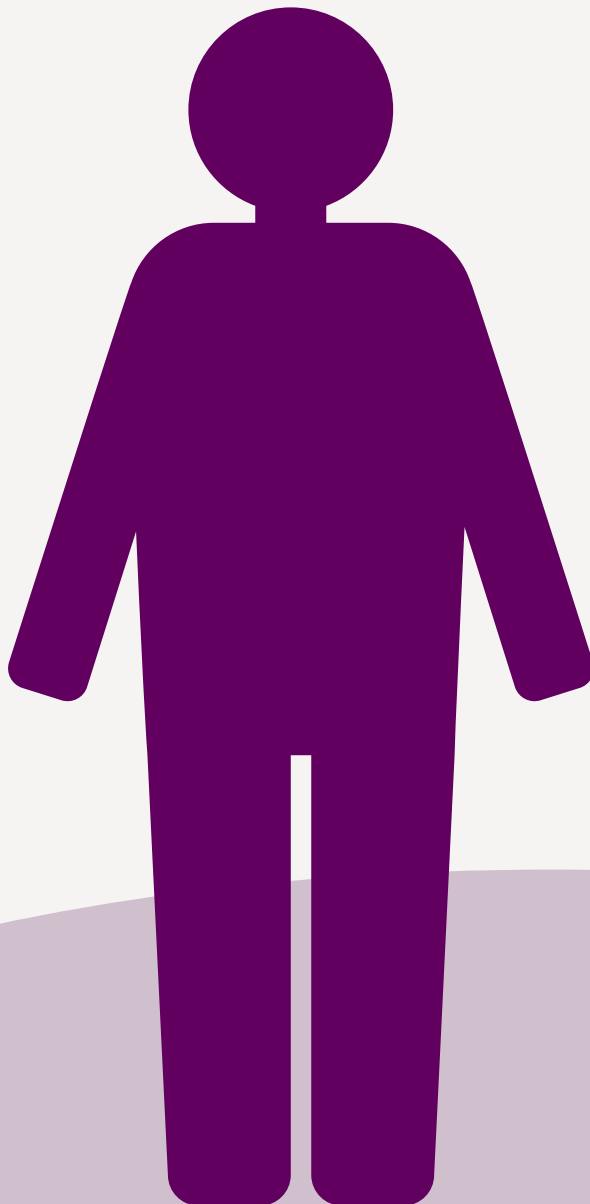
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Introduction

NHS National Services Scotland's, National Services Division, as commissioners of specialist services in Scotland, conducted a transplant recipient patient survey in 2020. To further explore results of the feedback received, the ALLIANCE was asked to host a series of focus group discussions with people that are resident in Scotland, and who have lived experience of engaging with solid organ transplant services as patients.

The focus group discussions were held on the 20th and 21st of April 2022 on Zoom, and were hosted by the ALLIANCE's Integration, Engagement and Lived Experience Hub. A representative from National Services Division shared the results of the survey, and highlighted the importance of patient feedback to drive service improvement and the development of more patient centred transplant services. Participants were divided into break out rooms, each assigned to a group relating to the organ they had transplanted. People were invited to share their experiences of engaging with services for:



Heart transplant

**Islet / Pancreas-
Simultaneous Pancreas
and Kidney (SPK)
transplant**

Kidney transplant

Liver transplant

Lung transplant

The aims of the focus group discussions were:

To identify what transplant patients need from transplant services.

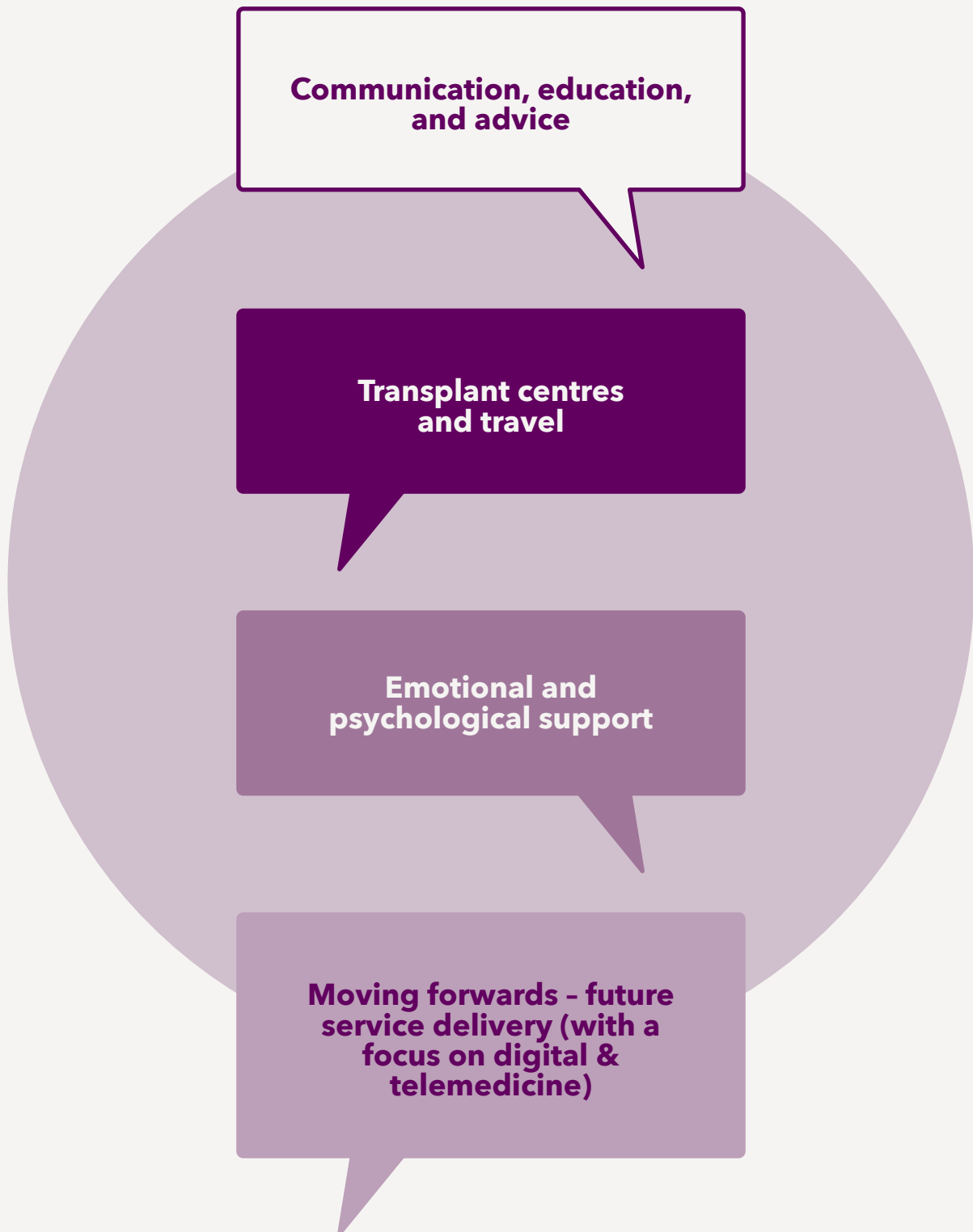
To identify areas for the improvement of transplant services, aiming to make services more person-centred and ensuring that people's needs are met in a consistent manner across Scotland.

To focus on the areas highlighted for improvement in the NHS National Services Scotland 2020 patient survey (particularly: emotional support for patients and their families; communication between transplant units, patients, local specialists, GPs; education and advice available to patients and their families).

To identify any service gaps that are specific to the transplanted organ.

To investigate views on the use of telemedicine for clinic appointments, remote monitoring, and online advice, reducing the need for travel.

As such, the questions asked during the focused group discussions centred on the following four key themes:



This report will outline the key points that people raised about their experiences around these four themes, with the aim of capturing what is going well and areas of improvement moving forward.

People's experiences of transplant services

Before moving on to more in-depth discussions, participants were asked: **What are/were the best things about your transplant service and experience?** The following general themes emerged across all breakout rooms:

Most participants spoke about the organ transplant journey as **"life-changing"**:



People explained that very shortly after their transplant they felt their quality of life had improved, and that a transplant offered a 'gateway' to recovery from illness. As one participant put it: *"You get your life back."*

Many shared stories of a **positive relationship with the organ transplant team**:



Most participants explained that this positive relationship was felt throughout the organ transplant process, from the moment a diagnosis was made.



Many spoke fondly of their transplant coordinators, some even referring to medical staff as *"family"* for the support they provided.



Some shared examples of good joined up work between medical teams, contributing to overall positive experience.

People appreciated when **information and advice was easy to understand and were they were given enough time to understand information given to them and ask questions.**

Heart Transplant Services

Location of heart transplant services: Golden Jubilee National Hospital, Clydebank

Number of focused group participants:

11

Communication, education, and advice

People generally felt that they had been provided adequate information and the right amount of information by their transplant team. Participants agreed that information shared in laymen's terms was particularly useful and appreciated, as this made it easier to understand and ask questions. Most participants explained that they felt comfortable directly contacting their transplant team if they had a question, and most participants said that they received information and answers to their questions in a timely way.

However, the experience was different for one person whose heart transplant journey began as an emergency. They explained:

“

The lack of information was more apparent for me, as I came in in an emergency. We were initially told that I wasn't a candidate for transplant, so there was a lack of clarity of what the options were. There was no real clarity, so by the time it [the transplant] happened there was no real time to find out anything.

Peer support and/or peer networks were widely quoted as an invaluable way of accessing and sharing information about the heart transplant journey, as shown in some key quotes by participants:

“

I had never been through surgery before, so I had no clue of what to expect. I made friends at the hospital and they explained, from personal experience, what it would feel like. Talking to someone with lived experience made a real difference.

“

Other patients in the ward were explaining how things work [...] peer to peer support made the experience less scary.



Peer support is incredibly powerful. The Jubilee [Hospital] connected me to a patient.



People in the wards who are ex transplant patients are a really big help. Until you meet someone who has been through it [the transplant journey] you don't know what it's going to be like.

The importance of peer-to-peer support was echoed by participants when asked if they would benefit from having access to a patient portal (website) with information about living with a transplanted organ:



It could be a thing that could be looked at, more so for the patients in the last few years, as they wouldn't have had the same opportunity to meet different people [because of the pandemic]. The portal could be used to connect people together, it's nice to chat with other patients.



I was bed ridden because I was on a balloon pump. if I could have been connected to other patients that would have been helpful.

This is in line with the comments participants shared on the importance of having quick and easy access to information about their transplant, that is in plain language.



Transplant centres and travel

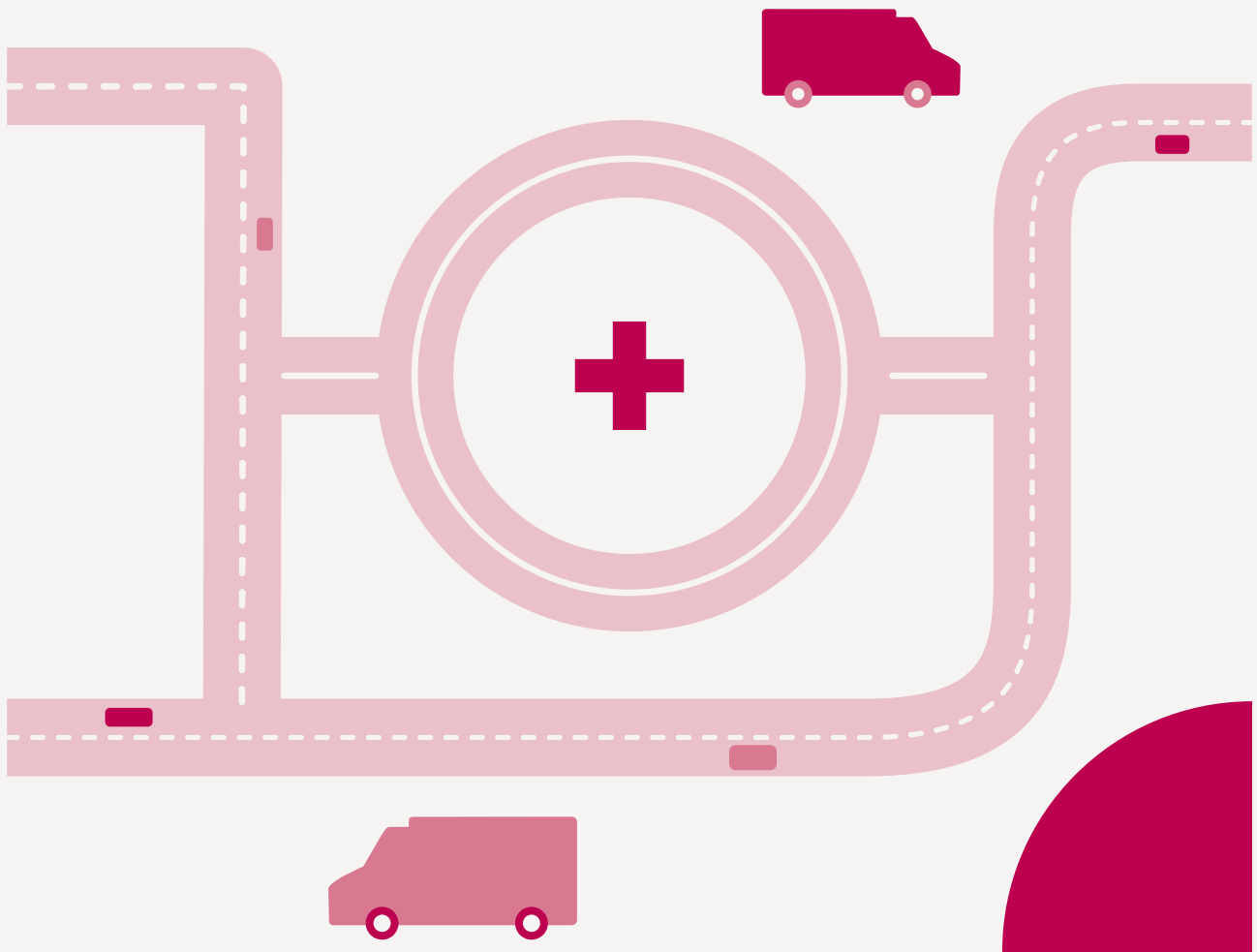
People's experiences with travel for appointments, procedures, and post-transplant care were very varied and dependent both on where in Scotland they were based, the modes of transport available to them, and their family/friend support network. Most participants, whilst describing having faced financial hardship at different times of their organ transplant journey, did not disclose being financially impacted in the long term by the process. Being compensated for travel and accommodation costs was appreciated by all participants, whether they travelled long or shorter distances to reach the hospital.

One of the participants who lived in a remote area reported having positive experiences of being transferred to the Golden Jubilee Hospital at different points of their transplant journey:



I live in Peterhead and got coast guarded; patient transfer was supplied all the time.

However, others who also lived remotely had less positive experiences; two participants reported being rushed to hospital (one via helicopter transfer and another via ambulance) but being left to make their own way back home after being told the organs were not available for transplant.



Emotional and psychological support

People's experiences of needing and accessing formal emotional and/or psychological support were mixed. Several participants explained being offered formal psychological support, and of finding it helpful. One person said:



I saw the transplant team psychologist. Speaking to him really helped.

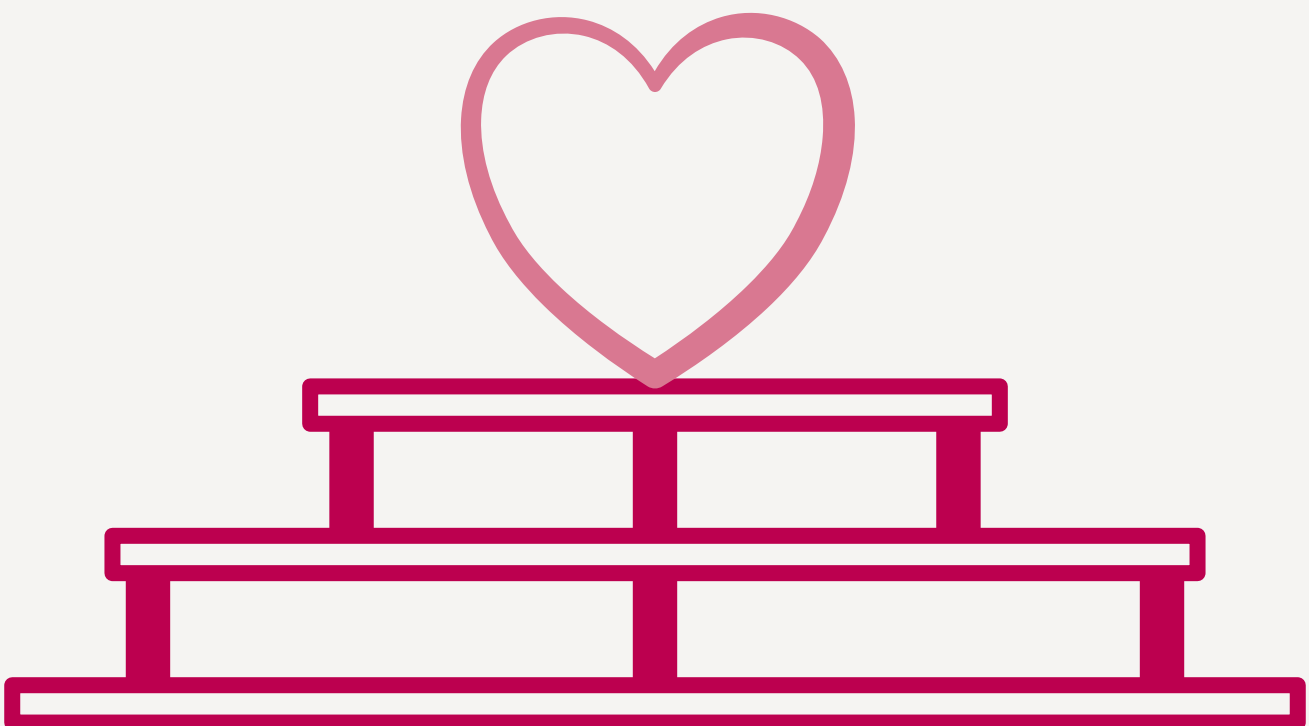
Some mentioned that accessing psychological support would have been more useful for their relatives than for themselves. The group agreed that formal support should be offered to all patients, although not everyone will want to access it or feel that it's right for them.

For many, in this group as well as others, being able to rely on peers who had been through the same experience was a key source of emotional support. People shared that being able to be part of peer support networks also felt like a an "*opportunity to give back*" to others, as expressed by one of the participants:



Speaking to other patients about my experience felt like I was giving something back, support own wellbeing as well as helping others.

One participant mentioned that peer support should be formalised, given how important everyone felt that it is to get through the transplant process.



Moving forwards – future service delivery (with a focus on digital & telemedicine)

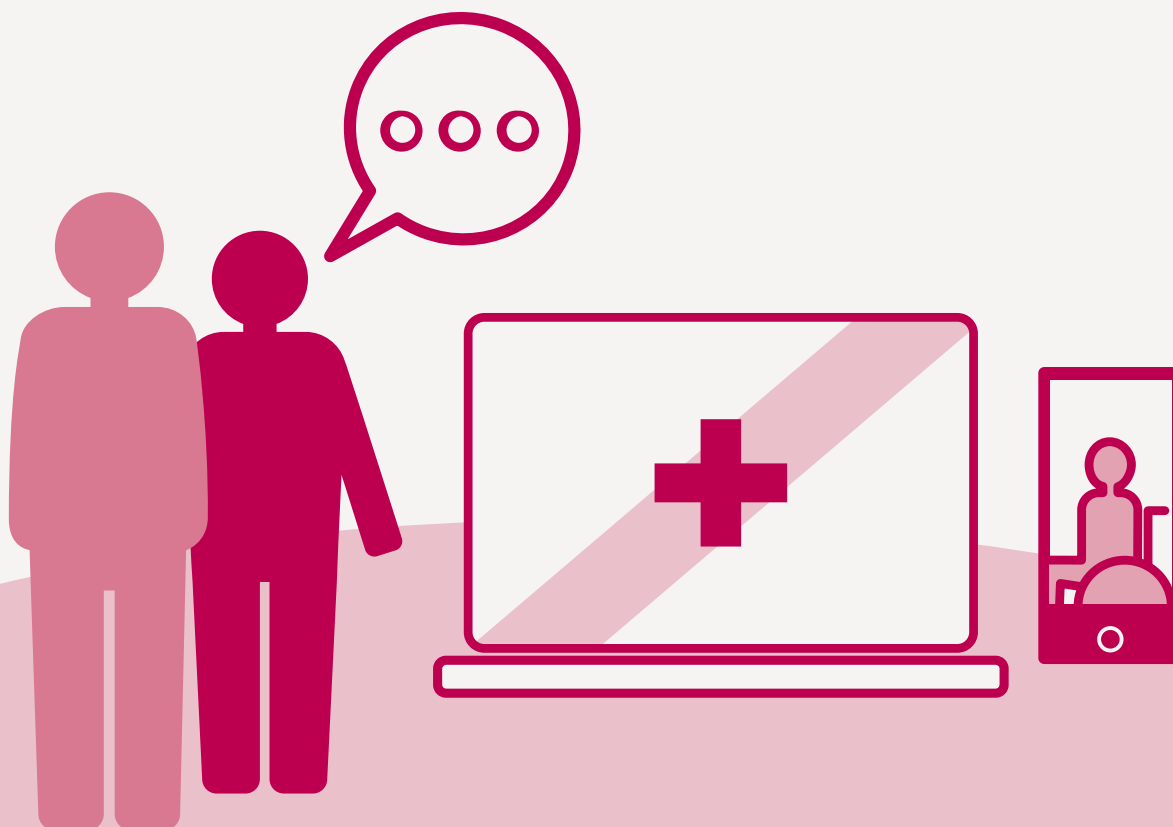
Views about accessing services and appointments remotely varied, although there seemed to be a consensus around when remote consultations were most useful. People tended to agree that it was good to turn to remote consultations for shorter discussions with health professionals. One person said:

“

It would be useful to have an online meeting with the consultant and transplant co-ordinator when it's just a discussion. It's an opportunity to have that conversation outwith the clinical space, not to replace the clinics but to have more of a brief before the actual clinical consultation.

Remote appointments were also thought of as beneficial to reduce traveling time and to avoid exposure to illness in clinical settings, particularly during the height of the pandemic.

However, the benefits of face-to-face appointments and services were also discussed by participants, many explaining that the sense of “connection”, trust, and reassurance that they had with their transplant teams and other medical professionals would be lost if all services were to be delivered remotely. All participants agreed that a mixture of remote and face-to-face delivery would work best, with patients always being given the option of which avenue to pick.



Islet / Pancreas- Simultaneous Pancreas and Kidney (SPK) Transplant Services

Location of Islet / Pancreas /
SPK transplant services for
Scottish residents: Royal
Infirmary Edinburgh

Number of
focused group
participants:

6

Communication, education, and advice

Participants in this group were generally satisfied with the information and communication they were offered by their transplant teams. Most participants explained that they felt comfortable directly contacting their transplant team if they had a question. However there was also general agreement that communication was better before their transplant had taken place than after. One person said:

“

Post-transplant, patients are sent around in circles regarding who to speak (GP to Team, Team to GP, etc.), there is no designated contact member and there is no communication between services.

Another participant shared:

“

Post-op care is not as personal as pre-op. I'm just told my test results but without much explanation. There aren't enough follow-ups.

The lack of understanding or specialised knowledge about organ transplant among medical professionals outwith the transplant teams was also quoted as an issue by some participants:



Other practitioners within the NHS but outside the Transplant Team don't understand what being a patient with transplant means, what being in the process means. This hinders receiving care in the NHS when needing to attend other parts of the system due to other health conditions.

People agreed that, for this reason, self-management was a "big part" of their lives. Thus, some participants shared that having access to better information about what would happen after their transplant, and any medication side effects, would improve their experience:



More information on the side effects is needed to give people a peace of mind that what they experience is normal. It is scary if no information is available and experiencing side effects at home with no medical support available.



More information on medication, their side effects, and dosage would be good.



The health issues due to the huge amount of medication that needs to be taken need to be discussed more.

Finally, when asked if they would benefit from having access to a patient portal (website) with information about living with a transplanted organ participants said they would use this predominantly to seek out peer support. As one person said:



Peer support online platform would be great for ad hoc questions, as often the [Transplant] Team is not seen for a while and individuals have to collect their questions during a longer period of time to be answered by the Team. Having the peer support online network would allow individuals to ask their questions and seek experiences of others on the topic. It would also reduce their isolation, which was worse during COVID as immunosuppressed people weren't allowed to leave the house. Also, just to have a place to moan and share frustration and happiness.

Transplant centres and travel

People's experiences with travel for appointments, procedures, and post-transplant care, were very varied and dependent both on where in Scotland they were based, the modes of transport available to them, and their family/friend support network. Most participants, whilst describing having faced financial hardship at different times of their organ transplant journey, did not disclose being financially impacted in the long term by the process.

Similar to other groups, people had more positive experiences of traveling to transplant centres if they had access to a personal vehicle or a support network who could help with travel. Those who had less positive experiences either lived remotely and/or had to use public transport to get to appointments:



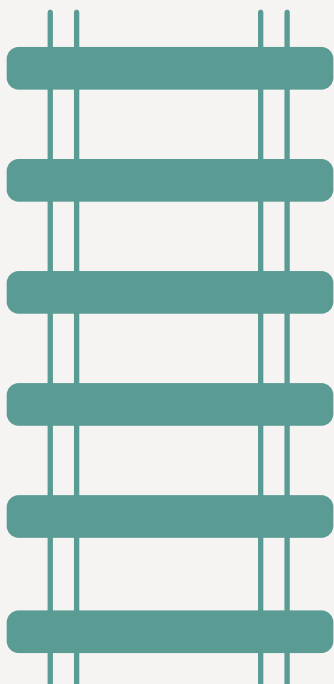
As it can take me around eight hours to get to Edinburgh, it would be good to have something [transplant services] further up North.



The issue is the post-transplant travel due to rush hour, I don't have family or friends available to help with transport, and I couldn't drive after operation.



For me it's logistical issues, as I have to take two buses and two trains to get to my appointments.



Emotional and psychological support

People's experiences of needing and accessing formal emotional and/or psychological support were mixed. Several participants explained being offered formal psychological support, and of finding it helpful. The group agreed that formal support should be offered to all patients, although not everyone will want to access it or feel that it's right for them; several highlighted that the support they received from family and friends was central for them. The role of charities was also mentioned as a valuable source of emotional and/or psychological support.

However, some participants also shared some negative experiences of not being aware that emotional and/or psychological was available:



I sought counselling, as the Transplant Team couldn't help, they referred me to a UK-wide charity who then offered counselling. But a local charity or support would have been better, not a UK-wide one. I was disappointed that I was not offered local support.



I felt alone, I didn't know anyone who had a transplant, and didn't know any charities who could support.

Finally, some people explained that being able to write a letter to the organ donor and/or their family was an important way to deal with the emotional and psychological aspect of the transplant journey.



Moving forwards – future service delivery (with a focus on digital & telemedicine)

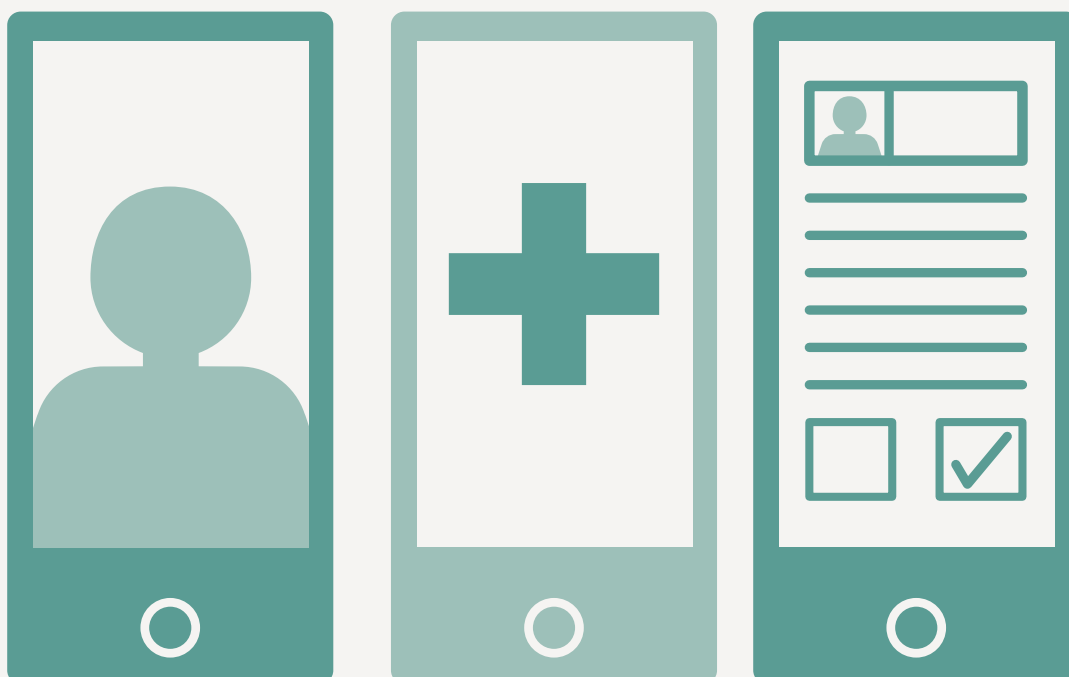
Experiences with telemedicine and digital services seemed to be more negative for participants in this group; several people related this to there being better communication before than after their transplant had taken place, and having to find themselves repeating their case to several different medical professionals. Lack of accessibility to the Near Me platform was quoted as a barrier by one participant who lived in a rural area in the north of Scotland, which led them to *“having to self manage a lot”* due to not being able to access appointments.

Some concern was also expressed about not having enough face-to-face appointments. One person said:



Without face-to-face appointments, things go missing; I haven't had any particular checks carried out [checks that should be part of the follow up appointments] for over two years.

Whilst the majority of participants in this group seemed to have had less positive experiences of telemedicine and digital access to services, there seemed to be a general agreement that a hybrid approach would be best, with patients always having an option of how they access appointments and information.



Kidney Transplant Services

Location of kidney transplant services for Scottish residents: Royal Infirmary Edinburgh and Queen Elizabeth Hospital, Glasgow

Number of focused group participants:

8

Communication, education, and advice

Participants in this group were generally satisfied with the information and communication they were offered by their transplant teams. Several highlighted that the level and quality of the information and communication they received was very much related to the relationships they had with their transplant teams and transplant coordinators. As one person said:



It's very important to have a good relationship with the transplant coordinator - I could contact them directly and that was excellent. Had lots of conversations and information sharing through that, no question was a stupid questions.

Participants also explained that access to sufficient and adequate information was linked to the timeline of their organ transplant process. Whereas those who waited longer on the list felt they had enough time and opportunity to ask questions and access the information they needed, others who had received a diagnosis and/or an offer of a transplant very suddenly had little time to understand and process the information shared with them. As one participant said:



I got the call late at night and the communication was very different [to how it was with my first transplant]. It was unexpected because it was a cadaver [organ donor], it came out of the blue. I felt clueless due to the unexpected nature [of the call] and wasn't prepared. Physically I was ok but emotionally it's hard to say, you just have to roll with it.

Finally, self management was described as important by most of the participants, who had an active role in monitoring their own conditions. For instance, most were able to read their own blood test results, and knew what was an abnormal result: "*kidney transplant patients tend to educate themselves about what those results mean,*" one person said. Another participant explained that they believed having good communication with their GP was about "self-education" and understanding that GPs are not expected to have specialist knowledge:



The main problem I see with the conversation is about self-education. What can a GP do, and what can a consultant do? The GP is not a specialist and is not expected to know lots of things about transplant. What can the GP do? If it's a kidney related problem, go to the specialist, if it's not, go to the GP.

However, concern was expressed that the people attending the focused group discussions all seemed to be confident self advocates, and that many people may be less informed about their care and the options available to them. One person asked:



What mechanisms are in place to support people to be self advocates? Many people just want to trust what the doctor says.



Transplant centres and travel

People's experiences with travel for appointments, procedures, and post-transplant care, were very varied and dependent both on where in Scotland they were based, the modes of transport available to them, and their family/friend support network. Most participants, whilst describing having faced financial hardship at different times of their organ transplant journey, did not disclose being financially impacted in the long term by the process. Being compensated for travel and accommodation costs was appreciated by all participants, whether they travelled long or shorter distances to reach the hospital.

For example, participants who lived close to the transplant centres, acknowledged that they did not feel representative of more rural communities. Most of them felt comfortable taking public transport (with a reduced cost due to free bus passes) or had access to a car. The biggest issue for this group was the cost of parking at the centre.

The experiences of those living remotely were different. A participant based in the Highlands described being listed on the transplant register at 3pm on a Friday, and getting a call telling them to go to Edinburgh within the next four hours to receive a transplant at 11pm. They had access to a vehicle, and thus could attend the transplant centre swiftly, but acknowledged that this is not the case for many people in rural locations. They counted themselves as "extremely lucky" that they were able to do this, and that their partner was able to take time off work at short notice to help care for them. They claimed that people who have no access to one's own mode of transport in the Highlands area are at a complete disadvantage when trying to easily access health care appointments and treatment. Indeed, having a family member to rely on for transport was crucial for most of the participants, and in some cases this could also pose a financial burden on families. One person said:



In the early days after transplant I couldn't drive and had to rely on my husband who had to take unpaid leave from work.

Similarly, the difficulty of getting to appointments relying on public transport were mentioned by one of the participants:



I had no issues getting to the local renal unit, but when I had to travel to a further clinic [Edinburgh], I don't think they appreciated where we lived, how far the travel was for me, and that I relied on public transport to get there. If I had a morning appointment I had to go the night before, and there wasn't any advice on how to organise this or get support - I later found out there were "proper" channels but didn't know about these at the time.

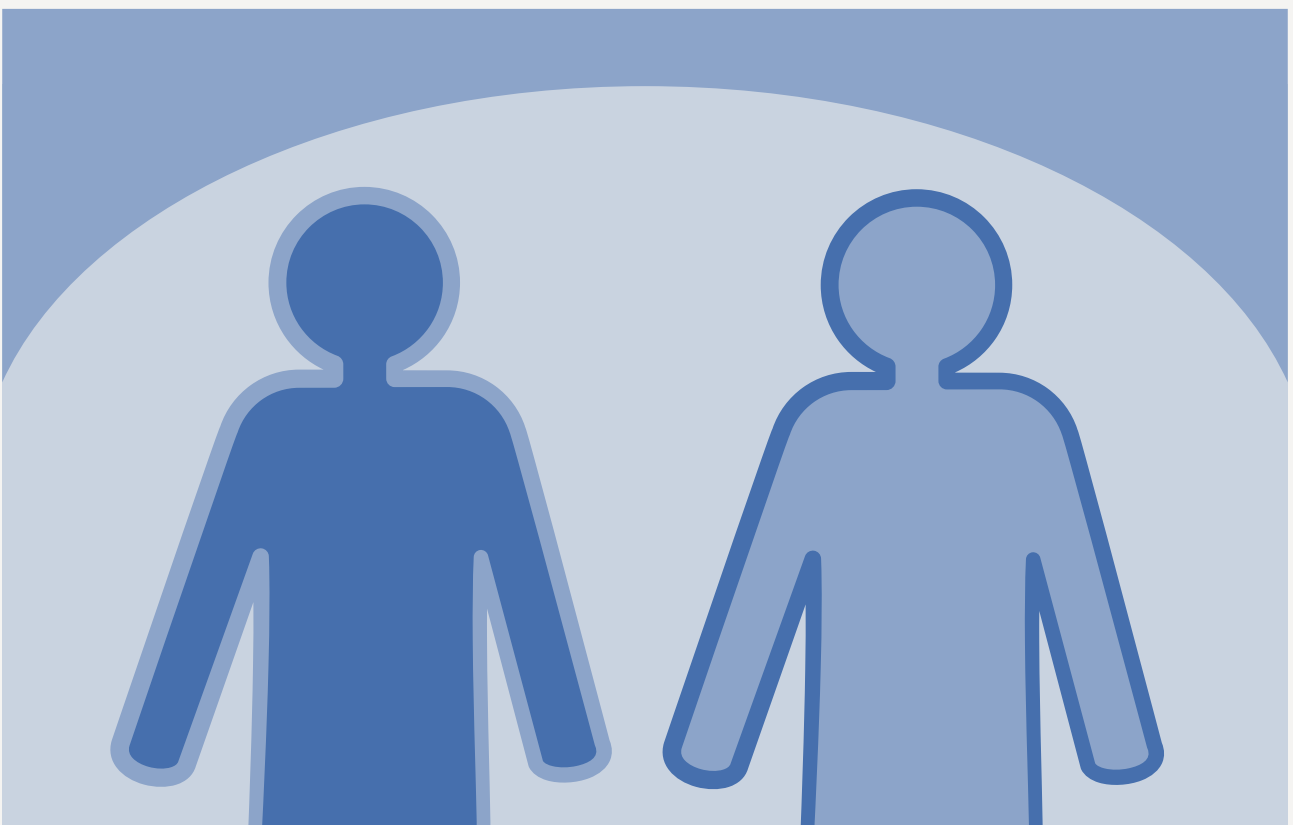
Emotional and psychological support

Most participants in this group discussions that they had not been offered any formal emotional support during or after their transplant, and that the majority of the emotional support they had received came via family and friend networks. Two participants detailed how much of an “emotional rollercoaster of a journey” their experience had been. One discussed feeling guilt post-transplant, as they had received an organ from a family member and often felt as if they “weren’t doing enough”. Another participant said it would have been nice to have a service to turn to for emotional support, and they are unsure if this exists. Others shared having experiences of sporadic availability to emotional support and psychological services, whether through hospitals or via other channels, such as charities. This was quoted as particularly challenging for those patients that may not have a family or friends support network:



Some people who are going through this experience don't have families; and they don't get asked how they're feeling [...] Access [to services] shouldn't be sporadic, everyone needs somebody when something happens; whether it's someone to have a laugh with, someone to have a cry with, someone to have a moan with.

A few others, however, felt as if they had no need for professional psychological support post-transplant, and had all had an overwhelmingly positive experience during their journey without it; this was noted as being “remarkable”, and probably not the common experience. They also expressed that the need for psychological support and/or treatment depended on each person.



Moving forwards – future service delivery (with a focus on digital & telemedicine)

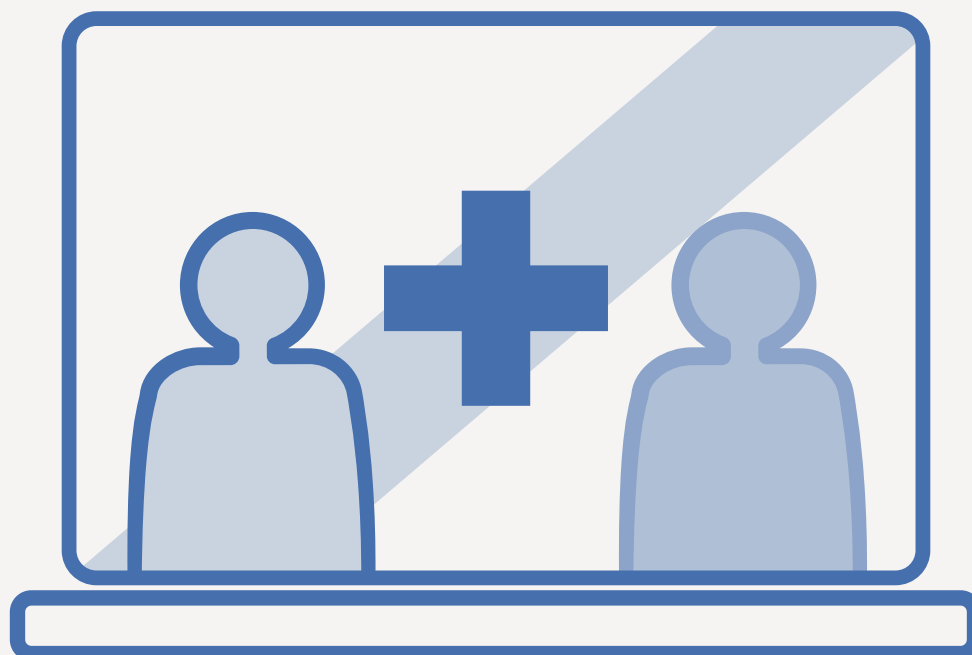
Discussion about remote delivery for this group centred on how things had changed during the pandemic. Topics discussed included the move to telemedicine platforms, and using Zoom, WhatsApp, and/or phone calls for appointments. One participant said they believed all medical appointments would continue moving this way, and this will not be an issue because everybody has managed and accepted it for the past two years. Two participants said that they would choose not to have a face-to-face appointment unless absolutely necessary; they claimed that they would only attend the hospital if they were feeling unwell.

Where it was agreed that face-to-face is especially important for post-transplant monitoring, where the patients need to be weighed, and the doctor must assess their eye colour, skin colour, and general appearance.

Being able to have a choice was quoted as very important by many participants, who said that they appreciated being able to have the possibility to change their preferences regarding online appointments as we move into different stages of the pandemic. One person said they had been offered the choice by their local centre, and had chosen Zoom appointments, however they added that, *"I would be very upset if I wanted a face-to-face and wasn't allowed one."* Another participant said:



I am happy with a mix of both but the face-to-face is really important as you explore information you wouldn't get by a [pre-recorded] video link. Things can just come up in a conversation. If it's a mix of both, then the consultant can see how you're reacting during the conversation as well.



Liver Transplant Services

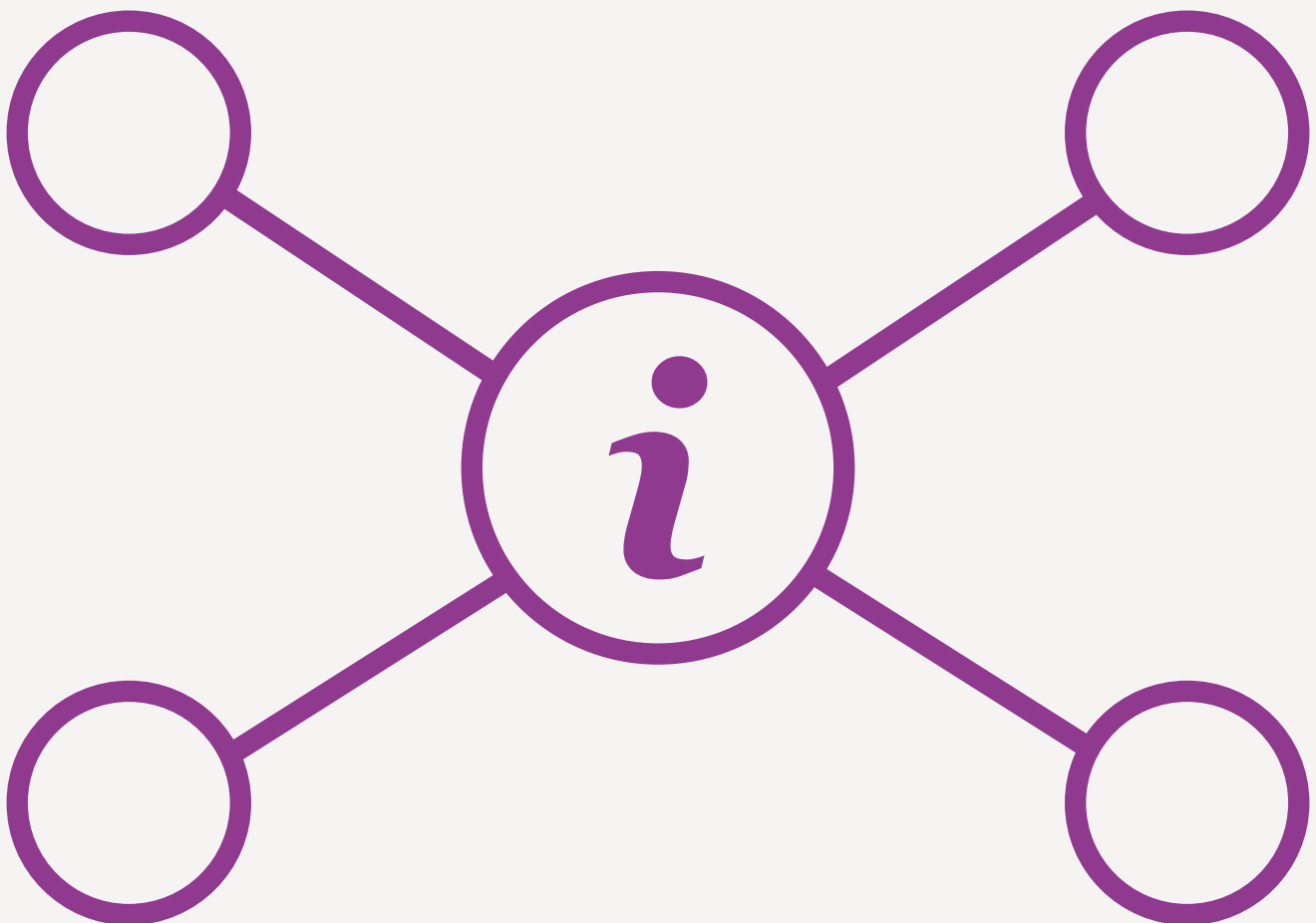
Location of liver transplant services for Scottish residents: Royal Infirmary Edinburgh

Number of focused group participants:

15

Communication, education, and advice

Participants in this group were generally satisfied with the information and communication they were offered by their transplant teams. Most participants explained that they felt comfortable directly contacting their transplant team if they had a question. Several highlighted that the level and quality of the information and communication they received were linked to their relationship with the transplant team and other medical professionals, as well as “knowing the system.” Like in other groups, there was also a sense that experiences with communication and accessing information were less positive post-transplant. An issue that was particularly challenging for this group was the lack of centralised communication between the transplant services and their local medical teams, as well as the patchy access to digital test results. Participants generally felt that having a trusted ‘central website’ with information for patients would be useful, as *“This would allow individuals to use it intermittently, when required.”*



Transplant centres and travel

People's experiences with travel for appointments, procedures, and post-transplant care, were very varied and dependent both on where in Scotland they were based, the modes of transport available to them, and their family/friend support network. Most participants, whilst describing having faced financial hardship at different times of their organ transplant journey, did not disclose being financially impacted in the long term by the process. Being compensated for travel and accommodation costs was appreciated by all participants, whether they travelled long or shorter distances to reach the hospital. Social workers were quoted by participants as helpful when navigating information about financial support for travel and accommodation.

The experiences of participants who lived rurally were mixed. One person who lived in Aberdeenshire shared a positive experience of being transferred to Edinburgh for appointments and of receiving financial support:



I was going down every week for my appointments; the Scottish Ambulance Service would pick me up at 6am, take me down to the hospital for lunch time and then take me back up. When my husband was staying in Edinburgh with me, all refunds for accommodation and travel were arranged through a social worker.

However, another participant who lived rurally in the West of Scotland, and whose child had received a liver transplant in England, described both the practical difficulties of getting to the transplant centre in England, as well as travelling to Glasgow for medical appointments:



People in the Glasgow team don't understand what it means to have multiple appointments every other week or so, and having to take a three hour round [car] trip each time. There needs to be more joined up approach for appointments.



Emotional and psychological support

People's experiences of needing and accessing formal emotional and/or psychological support were mixed, however most participants in this group explained that they had a negative experience when it came to receiving this kind of support, and of encountering 'sporadic' availability of services. Several people shared that they had been offered little or no support:



Never received any emotional support at all, just had support from family and friends, no emotional support from the transplant team.



There was no offer of counselling or involvement from mental health services. I don't remember ever having a discussion about mental health support.



It's very much about the physical aspect but no discussion about the emotional aspect.

One participant described a positive experience receiving support from their GP:



I received a lot of my emotional support from my GP at the time [of my diagnosis]. He was excellent. What he didn't know, he would find out. He restored my faith in doctors. Our local hospital didn't know what was wrong with me for three and a half weeks while I was in liver failure. Sadly, my GP has now emigrated to New Zealand. I am devastated. I don't get the same support any more.

The group also agreed that formal support should be offered to all patients, although not everyone will want to access it or feel that it's right for them. Finally, peer support was highlighted as an important source of emotional and psychological support:



It would be great for peer supporters to be trained and to make space for these interactions to take place in hospitals.

“

The most important support has been from other families that have gone through this experience.

“

People are more comfortable talking to people that have had the same experience, less so with those that haven't. If I can give something back [by providing peer support] then I would like to.



Moving forwards – future service delivery (with a focus on digital & telemedicine)

Views about accessing services and appointments remotely varied, although there seemed to be a consensus around when remote consultations were most useful (especially to avoid traveling long distances or to avoid risk of infection during the height of the pandemic):

“

It depends on the circumstances, if I was really unwell I would feel more reassured if I can see someone in person.

“

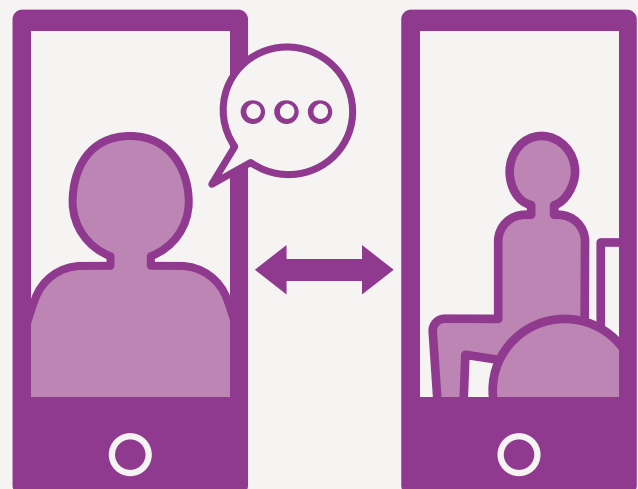
Some people might be more comfortable in their own home, so telemedicine could work better for them.

“

During COVID-19 Near Me was easier and safer, was better knowing I didn't have to be near hospitals. If I felt I needed to see a person all I had to do was to pick up the phone - for myself I felt the choice was there. I have confidence I would be seen in person if I felt unwell; but for five minute appointments it's better to have Near Me.

“

Face to face is nice - but I was getting quite scared through the pandemic, so I was glad for the phone appointments.



The importance of face-to-face appointments was also highlighted as particularly important by a participant whose child had a liver transplant:



For paediatric patients it's really crucial to have that face-to-face contact, having relationships and emotional support with the same person is very important, and face-to-face makes children confident but [my child] wouldn't be so comfortable with telemedicine.

The topic of having choice over what kind of service delivery is available to patients was brought up quite strongly in this group:



As long as telemedicine is given to us as a choice and not imposed then it's fine. A lot of people will struggle with technology, and this will add to the stress and not ask questions they might need to.



It's all a matter of choice and we don't often have that choice.

The group also discussed the importance of online support forums on Facebook; one participant claimed they did not seek out peer discussion or support meeting groups like the other participants, but instead liked to read stories others had shared about their experiences on Facebook. They did say, however, that they did not feel comfortable to share their experiences on these Facebook groups. This liver transplant support group on Facebook was known and appreciated by others. Someone said: "There is always someone to ask a question to, or if anyone needs picked up [from a medical appointment] they will pick you up, it's amazing." WhatsApp groups were also mentioned by some as an important platform via which peer support could be sought:



It's good to know you're not alone. And in our WhatsApp group, we all look out for each other.

Lung Transplant Services

Location of lung transplant services for Scottish residents: Freeman Hospital, Newcastle

Number of focused group participants:

12

Communication, education, and advice

Participants in this group were generally satisfied with the information and communication they were offered by their transplant teams. Most participants explained that they felt comfortable directly contacting their transplant team if they had a question. Nonetheless, many said that communication between the hospital in Newcastle and local services was often fragmented. Like other groups, some mentioned that the quality of information and level of communication was better pre-transplant than post-transplant. Some of the positive experiences that participants shared:



Treatment at Newcastle was very good, and felt I couldn't be advised any better in terms of staying as healthy as I could. I felt the connection between Inverness and Newcastle was also effective.



From the minute you go for your assessment for a lung transplant, until you reach Newcastle, all information given is amazing, I was overwhelmed by how much they do for you and let you know. It feels like you are important to them.



People who have been spoken to before going in for a transplant feel a lot more prepared to deal with what is ahead of them.

Some participants had a less positive experience with receiving information and with communication, they explained:

“

It's important speak to someone before you go into theatre, talk about what is ahead of you, because you aren't prepared. More guidance, advice and support from professionals is needed, we need to have open, honest and upfront conversations. But in moderation, you also don't want to put people off too much with worrying about the after effects.

“

Many only get as far as processing the phone call to go to Newcastle. Until you are living through it you don't know what to expect, like the healing process and how long it will take you to recover, how you will feel when you wake up...

“

We need more help to prepare and to prevent feelings of guilt from happening in the future. We need to know how long recovery can take in a real life sense, and be told in open and honest way about side effects of medication, how every person recovers and reacts differently, it's important.

On services fragmentation, these were some of the comments that participants made:

“

Everyone is positive about the Golden Jubilee, but local services are a lot more fragmented. GP services will be different in different local areas. I was getting sent wrong medication, and misdiagnosing symptoms was common.

“

If you go to GP, they say they 'can't do much about it' and say you should reach out to Newcastle and vice versa. Both don't really know who should be helping.

When asked if it would be useful to have access to a patient website or portal about living with a transplant, participants were generally positive about this possibility, mainly as a way to find information easily and quickly. One person said:

“

I would rather look up information on a trusted website rather than phoning and bothering people straight away.



Transplant centres and travel

People's experiences with travel for appointments, procedures, and post-transplant care, were very varied and dependent both on where in Scotland they were based, the modes of transport available to them, and their family/friend support network. Most participants, whilst describing having faced financial hardship at different times of their organ transplant journey, did not disclose being financially impacted in the long term by the process. Being compensated for travel and accommodation costs was appreciated by all participants, although some participants said that people who are earning a wage do not get reimbursed for travel expenses, which can be an issue at times. In addition to the questions that all participants were asked in other break out rooms, lung transplant recipients were also asked:



Would your experience have been improved if there was a Scottish lung transplant centre?

People explained they would prefer to go to Newcastle because they know it is a specialist service, with several explaining they did not mind travelling because it was a worthwhile experience, and their medical teams were welcoming and supportive. One participant said, *"Going back to Newcastle is like going back to see your family."* Some also said they go down for a couple of nights and see Newcastle while they are there, making it a mini break/holiday.

In terms of having a lung transplant centre in Scotland, some participants who lived in remote/rural areas said that having a centre in Glasgow or Edinburgh would not make a big difference, as it would still be difficult for them to get to.

Some participants spoke of experiences of wasted travel: *"Getting a call and getting told, 'No' when you get to the centre is disheartening."* Many said they did not find the need to travel as a burden, *"but it can be annoying if you only go down and are there for only 10 minutes, some things could be done online if this was the case."* Others explained how physically demanding travelling a long distance had been for them and their support networks, with some experiencing being sleep deprived whilst driving, for example.

A lack of joined up working across local services and the transplant centre in Newcastle was also quoted as causing issues with transport by some participants. As one person said:



There have been a number of times when the hospital have asked to do the same tests I had already done. When going to the Newcastle centre I make sure all tests have been done right, but often I need to redo the tests, as local service and specialist service lack communication.

Emotional and psychological support

Access to formal emotional and/or psychological support seemed to be additionally difficult for lung transplant recipients:



It would be important to have a link in Scotland to discuss how people are feeling, I had a lot of guilt and carrying this around was hard. I needed someone to talk to about this, felt like you had gone through a sort of trauma.



Newcastle should put in place ongoing support for when you come back to Scotland, felt grateful after the operation but there is ongoing guilt about what the other [organ donor's] family is going through.



It would be useful if something could be implemented for lung transplant patients that is similar to Marie Curie/Beatson.

Lung transplant recipients' accounts were particularly telling of the need for formal emotional and/or psychological support during the post-transplant phase of people's journeys, during which many spoke of dealing with "survivor's guilt" and also needing reassurance about their post-transplant experiences, side-effects, etc. The important role that peer support played for people was also highlighted in this group, with one participant saying: *"It's hard to explain to someone who hasn't been through it how this feels, there could be a formal peer support group for people who have also been through the process."*

When asked what support should look like, participants said:



There should be a link in Scotland to discuss how people are feeling, I had a lot of guilt and carrying this around was hard. I needed someone to talk to about this, I felt like I had gone through a sort of trauma.

“

Newcastle should put in place ongoing support for when you come back to Scotland, felt grateful after the operation but there is ongoing guilt about what the other [organ donor's] family is going through.

“

There also needs to be support for relatives who are supporting people going through a transplant, it's vital both for people who have been in this position as well as their family members.



Moving forwards – future service delivery (with a focus on digital & telemedicine)

Views about accessing services and appointments remotely varied, although there seemed to be a consensus around when remote consultations were most useful especially to avoid traveling long distances or to avoid risk of infection during the height of the pandemic:



It can be too much travelling every three months, reduction in frequency of visits would be useful with telephone consultations in between appointments.

However, several participants explained that face-to-face consultations to be physically assessed were especially important to them:



The pandemic caused delays in receiving help face to face, and it's difficult to diagnose symptoms over the phone, for example breathlessness is often misdiagnosed or not taken seriously.



The pandemic meant there were delays in receiving help face to face, and it's difficult to diagnose symptoms over the phone, like breathlessness, it is often misdiagnosed or not taken seriously.

Finally, the importance of peer support was again highlighted by this group. One participant said:



Peer support is needed, like a buddying system from someone who has been through it before you go through the process would be helpful, because you don't think about the after effects when you are going through it.

Concluding remarks & considerations

Across groups, these were some of key priorities identified for improving all transplant services moving forward:

- Access to a 'named contact':



Having a named consultant made a huge difference, I can always contact them and receive speedy response and care if I am worried about something.

- Joined up working & better communication between medical teams:



There is no communication between locations, for example between council areas and health boards, nor across services, making it hard for patients to be treated and causing high amounts of stress to them, along with causing deterioration in their health as well.



A joined computer system across Scotland would be good.

- Improved communication within hospitals:

“

There is a lack of joined up working in hospital. I was in hospital for eight hours fasting before my scan. I was then asked by another department to go for another scan. I ended up fasting for eight hours with no food or water. My blood sugar crashed and they got really worried about me, the communication between departments in hospitals is awful.

“

Services should feed back to one another to make sure that things are not overlooked and a holistic care is delivered.

- Investing in peer support:

“

Having a peer support group would be amazing, if they offered this to people. As much as medical team in Edinburgh have been amazing, they haven't had liver transplants. That lived experience is important.

“

Peer support is the way forward. I know how it works as I deal with it at the transplant unit. It helps you get through the whole transplant thing and the hospital experience.

- Professional development for medical staff & addressing stigma:

“

When I was first diagnosed with liver disease I was given no information on what to do with regards to my diet.



I had a bad experience with stigma. The nurses taking blood at my GP asked if I was a boozer because I had a liver transplant. There needs to be information given to the people who are involved in care.

- **Improving the complaints process:**



There isn't an easy way of complaining, no anonymity is ensured when putting a complaint in, which prevents patients to raise problems as they are scared how it would come back at them, as everyone in the Team would know that they complained.



I didn't want to make a complaint, I just wanted to move on from the experience.

As highlighted throughout this report, people's experiences of organ transplant services are varied and mixed. In addition to the considerations highlighted around people's socioeconomic backgrounds and access to technology, the ALLIANCE recommends that further engagement with people with lived experience, of a diversity of backgrounds, is carried out to fully understand the full range of experiences before making improvements to services. This includes engagement with people who may not have opportunities to take part in online discussions such as the one carried out by the ALLIANCE, or who may not have been able to complete the NHS National Services Scotland 2020 patient survey. Engagement activities also need to be carried out with those who may have communication support needs to ensure their experiences are also properly captured and considered when developing patient experience improvement plans.

It also needs to be noted that participants who attended the focused group discussions hosted by the ALLIANCE were all at very different stages of their organ transplant journeys, some having had a transplant over a decade before the focused group discussions took place, whilst others were still on the transplant waiting list.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

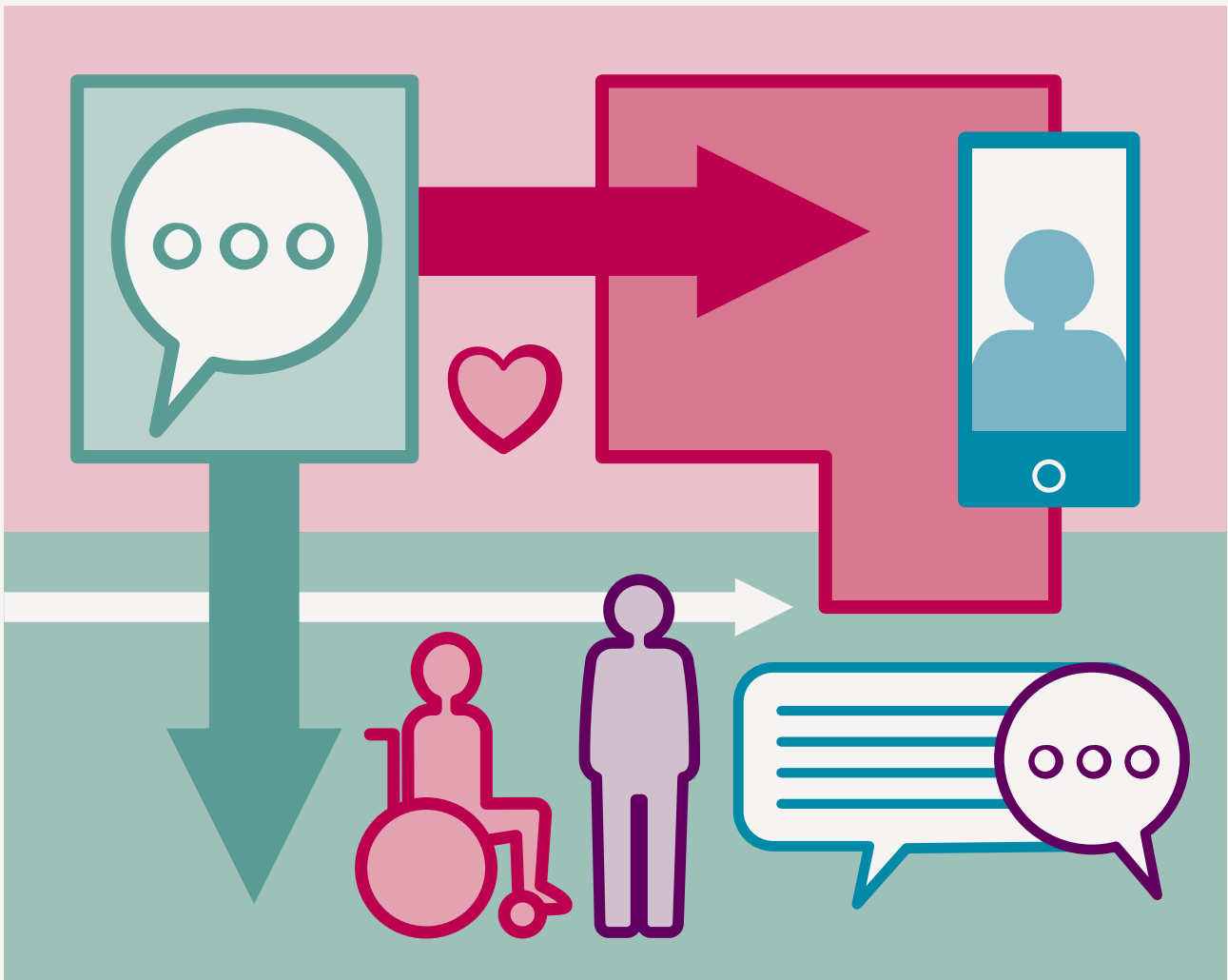
Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. We seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre



Contact:

Francesca Vaghi, Senior Development Officer

E: francesca.vaghi@alliance-scotland.org.uk

Kerry Ritchie, Programme Manager

E: kerry.ritchie@alliance-scotland.org.uk

☎ 0141 404 0231 ✉ info@alliance-scotland.org.uk 🐦 @ALLIANCEscot 📘 ALLIANCEscot

📷 alliance.scot 🌐 alliancescotland 📺 alliancescotland 🎧 ALLIANCE Live

www.alliance-scotland.org.uk

Health and Social Care Alliance Scotland (the ALLIANCE)

Venlaw Building, 349 Bath Street, Glasgow, G2 4AA

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