Experiences of telephone consultations: Results of a telephone interview project in haematology and oncology

Summary:

- 48 patients interviewed about telephone consultations across haematology and oncology.
- Results and recommendations consistent with research emerging from other centres and national charities.[1]
- These results pertain to telephone consultations and not to the experience of Attend Anywhere.

Themes:

- Huge benefit in saving time, stress, and expense of travel to Oxford and finding somewhere to park the car. This includes saving difficulties associated with caring responsibilities and working life. People find it more convenient, and can feel more relaxed having the conversation at home.
- Most people state that they feel able to have the same conversation with the health care professional as they would if the meeting were face to face. It is just as easy to find out what they would like to know.
- It helps if you have met the person calling you before. In cases where the two parties have not met before, it is essential that the HCP is prepared for the call, has read the notes and does not ask the patient to repeat information that the HCP is expected to know.
- The principle disadvantage is the fact that a physical examination cannot take place. For those who are on 6 monthly follow up, this might mean 12 months between physical examinations, which for some patients will be a cause for concern. But for those with illnesses that are monitored with blood results telemed is an ideal arrangement.
- Patients are reassured to know that they can telephone if there is a problem. They like to know that they can see their HCP face to face if necessary.
- Some people state that they would prefer to have some face to face consultations if possible – would not like care to be exclusively via telephone or video. These people are more likely those that feel unstable or those that have only recently completed treatment.
- Patients recognise that some staff are better at remote consultations than others; speaking over the phone requires a different set of communication skills.
- It is easier to withhold information over the phone – “stiff upper lip”, or fear of acknowledging something worrying.
- People acknowledge the loss of visual cues. Some feel that video consultations might help: you can see facial expressions, share images or show the HCP a wound or rash. However, many express reservations about video consultations and would prefer a choice.
- It is harder for significant others to take part and a risk that their input is lost.
- It helps to prepare for your appointment.

[1] See, for example https://www.nationalvoices.org.uk/publications/our-publications/dr-will-zoom-you-now-getting-most-out-virtual-health-and-care

Implications for practice in our Directorate:

- Remote monitoring is welcomed by most patients as a safe, sensible and convenient improvement to our service.
- It is important to introduce yourself properly: use your title, state the clinic you represent, and put yourself in context ("we met when you attended Dr C's clinic in January"; "we haven't met before but I work with Dr F's team at the Churchill hospital").
- Consider appropriateness of patients for telemed: disease group, anxiety levels, treatment history. Provide telemed patients with information / reassurance about the lack of physical examination appropriate to the tumour group.
- Ask people about their preferences. Invite patients to express a preference for video or telephone consultations. And share information with patients about favourable experiences of Attend Anywhere.[2]
- Reassure patients about the availability of face to face appointments should there be the need for one. The patient should be reassured that they can request this.
- Adequate training and supervision should be available to HCPs in communicating via telephone / video.
- Important that the call is as close to the stated appointment time as possible. Provide the patient with a window within which to expect the call.
- Consider how to ensure appropriate input from carers / spouses. These people are often key contributors to patient care and might feel excluded from a phone call. Ensure that patients know that other people can be invited to an Attend Anywhere meeting, even if they are not in the same place.
- Develop resources to encourage patients to prepare for their appointment: symptoms to be aware of or make note of; questions they would like to ask; consider where to take the call and who might be with you. Encourage people to identify a private and comfortable place where interruptions will be avoided.

[2] Survey responses elicited following the Department's Attend Anywhere consultations suggest that 95% of patients would agree to have an AA consultation again, and 67% agree or strongly agree that they are just as good as face to face consultations.

1. Introduction

Since March 2020, our directorate has changed a significant proportion of its face-to-face outpatient appointments to telephone consultation or Attend Anywhere video consultations. The directorate had some experience of telemed, as several teams had already begun regular telephone follow up for certain groups of patients. A pilot of Attend Anywhere had begun, including some clinical teams working in our directorate, but at the time of the pandemic the take up had been very limited. However the imperatives of the COVID-19 pandemic, and the need to reduce risk of exposure to vulnerable patient groups, meant a sudden reorientation of our work in favour of keeping the majority of our patients at home for clinic appointments. As the virus is likely to remain prevalent for the foreseeable future, and as risks to our patients remain, we anticipate continuance of telemedicine in the medium to long term.

But what has this been like for our patients? In April of 2020, we decided to embark on a telephone interview study with patients from across our disease groups to attempt to answer this question. Interview studies of between 15 and 30 people are well established in qualitative work looking at patient experience. They provide timely feedback and potentially rich experiential information, allowing patients to share ideas and opinions that are difficult to anticipate or to ascertain with other qualitative approaches.

Initially, interviews were carried out with 30 patients from haematology. There was a plan to expand to the same amount of interviews with people from teams in Oncology, and 18 interviews were completed. As these interviews were producing information consistent with what haematology patients were saying, and as no new themes were emerging, it was decided to end the interview project with these 48 patients. Interviews can be intrusive for patients and they are labour intensive; for these reasons it is accepted in qualitative research methodology that a project can be suspended when sufficient consistency of response has been established.

The aims of the study were:

- to establish how people feel about telephone consultations compared to face to face appointments;
- to establish whether people would be happy to continue with remote follow up and under what circumstances;
- to find out what we, as a department, can do to ensure the success of telephone consultations;
- to ‘sense test’ preferences for video versus telephone consultations.

2. Process

Colleagues identified patients from their telephone clinic lists. These patients were asked if they would be willing to take part in a telephone interview of approximately 15 minutes duration, and if they consented to take part their details were emailed to the interviewer via a secure nhs.net account. Invitations to participate were also sent to members of the haematology department’s patient engagement group, the Oxford Blood Group, and support groups including the Oxford myeloma support group.

Patient contact details were obtained from EPR. If email addresses were available, the patient was sent an email inviting them to respond with a suitable time and day for the telephone call. In the absence of an email address, the phone call was made 3 – 7 days following the consultation. The interviews were conducted by the Haematology Quality Manager, who has experience of qualitative research and patient interviews.

The interview began with a description of the rationale for the project. Participants were advised that the department wanted to learn from patient experience. They were told that their identity would not be revealed but that themes that emerge from the interviews would be shared with colleagues across the Directorate.

The following questions were used to guide the interview content:

- What has been your experience of telephone consultations so far? Do you feel that it is safe for you to be monitored in this way?
- Do you think that telephone consultations have any advantages or disadvantages compared to face-to-face appointments?
- Would you feel comfortable with further telephone consultations in future?
- Would you be interested in a video consultation if it was offered to you?
- Do you have any further comments about telephone consultations or our current service?

The interviews were semi structured to allow the participant to share opinions, feelings or anecdotes that they felt were most pertinent. This also allowed the interviewer to follow up on issues raised and ask further questions as appropriate.

The interviewer took notes during the conversation. These notes were typed up and the text analysed to identify common emergent concerns and themes.

3. Participants

People agreeing to interview came from the lymphoid, myeloid and BMT clinics in haematology and the radiotherapy and urology departments in oncology. Most of the haematology patients were people with a relatively long relationship with the department – 26 out of 30 had been patients in the service for longer than 5 years. Patients from oncology had, overall, a shorter relationship with OUH.

Gender	Age	Diagnosis	Most recent treatment history
M	60's	Mantle Cell Lymphoma	Autologous SCT Autumn 2019
F	80's	T-cell large granular lymphocytic leukaemia	No SACT, managed with blood transfusions
M	50's	Chronic Lymphocytic Leukaemia	Ibrutinib
F	70's	Chronic Lymphocytic Leukaemia	Ibrutinib
M	50's	Chronic Lymphocytic Leukaemia	Ibrutinib
F	20's	Hodgkin lymphoma	Autologous SCT Winter 2019
F	30's	Hodgkin lymphoma	Allogeneic SCT 2016
F	40's	Polycythaemia	No current treatment
F	30's	Chronic Myeloid Leukaemia	Clinical trial since 2017
M	60's	Chronic Lymphocytic Leukaemia	Ibrutinib
F	60's	Waldenstrom's Macroglobulinaemia	Watch and Wait
F	60's	Haemophilia: Von Willebrand Disease	Transfusions as necessary
F	60's	Acute Myeloid Leukaemia	Allogeneic SCT 2017
M	60's	Burkitt's lymphoma	Chemotherapy ended June 2018
M	60's	Multiple Myeloma	Allogeneic SCT 2013
M	50's	Primary CNS Lymphoma	Chemo + Auto SCT 2018
F	50's	T-cell lymphoma	Allogeneic SCT Feb 2020

M	60's	Chronic Lymphocytic Leukaemia	Allogeneic SCT 2018, now on CT
F	70's	Multiple Myeloma	Last chemo 2016
M	60's	Multiple Myeloma	Autologous SCT 2019
M	20's	Acute Lymphocytic Leukaemia	Allogeneic SCT Dec 2019
F	60's	Follicular Lymphoma	Allogeneic SCT 2019
F	60's	Multiple Myeloma	Autologous SCT 2015
M	50's	Chronic Lymphocytic Leukaemia	Allograft Nov 2019
M	50's	Multiple Myeloma	Autologous SCT 2019
M	60's	Multiple Myeloma	Allogeneic SCT 2019
F	50's	Multiple Myeloma	Autologous SCT March 2020
M	60's	Multiple Myeloma	Currently having chemotherapy
M	60's	Multiple Myeloma	Last chemotherapy 2019
F	50's	Endometrial carcinoma	Treatment ended Feb 2020
F	60's	Endometrial carcinoma	Treatment ended Sept 2020
F	60's	Breast	Treatment ended March 2020
M	70's	Astrocytoma	Still in treatment
F	40's	Astrocytoma	Treatment finished Dec 2019
M	70's	Rectal carcinoma	Treatment finished June 2020
F	60's	Breast	Treatment finished Feb 2020
F	70's	Breast	Treatment finished March 2020
M	40's	Hodgkin lymphoma	Treatment ongoing
F	80's	Breast	Surgery Jan 2020 then RT finished March 2020
M	40's	Sarcoma	Treatment ongoing
M	60's	Prostate	RT finished 2018
M	70's	Prostate and tongue	RT finished 2016
F	40's	Breast	RT finished June 2020
F	50's	Breast	Surgery 2019, then chemo and RT finished in March 2020
M	70's	Prostate	RT finished 2018
M	70's	Prostate	RT finished 2019
M	70's	Prostate	Diagnosed April 2020, pending treatment

4. Results

4.1 What has been your experience of telephone consultations so far? Do you feel that it is safe for you to be monitored in this way?

- People have had positive experiences of telephone consultations on the whole and for the majority of people interviewed it is a sensible solution; it makes people safer from COVID19, but it is also a convenience and a saving in terms of time, resources and stress.
- Participants report that colleagues have been helpful, polite, and that sufficient time is allowed for the necessary conversation.
- People report that they can usually have the same conversation over the phone as they would in person, although there are some losses associated with loss of body language, social interaction and non-verbal cues (see 4.2 below).
- People recognise that the COVID-19 pandemic has precipitated this change in practice and agree that it is far better to avoid the risk associated with travel to hospital. For this

reason, people feel safe with telephone consultations because of the reduced risk of viral exposure.

- The participants also discussed 'safety' in terms of the safe monitoring of their illness. The loss of a physical examination is worrying for some patients, whereas those who have a condition that is easily monitored with blood tests do not express concern about physical examinations.
- Safety is also related to familiarity with the health care professional (HCP) and the reassurance that the person they speak to knows their situation. It does make a difference if the patient has met the HCP before in person – the knowledge of what someone looks like, and a prior history, help compensate for not seeing them in person. HCPs who have not met the patient before can help this situation by clearly introducing themselves, acknowledging that they have not met before, and stating their role and the team they are part of.
- Safety also means knowing that you can call – and see someone face to face – if there is a problem or cause for concern. The CNSs are frequently mentioned for their excellent supportive care and for reliable, timely and empathic responses to queries. It is critical to know that this part of the service is unchanged and there if they need it.
- It is critical that the person making the call is familiar with the patient's history and has read the notes in advance of making the call. Failure to do so undermines trust and confidence: any participant who had a negative experience of telephone consultations cited failure to read the notes as the main reason that the call did not go well. Similarly, having to repeat one's medical history undermines confidence: "they should know that already…"
- Some people express concern that people don't seem to know what is going on in other departments – especially those who are under the care of more than one service. This can create confusion for patients and can undermine confidence in OUH – "to the patient, you are all one organisation."
- Safety is also contingent on a degree of awareness of one's own illness. Those with a longstanding illness know what language to use; they know what the clinician will want to know and they are familiar with the setup at OUH. Those who felt less safe were those who have conditions that might require physical examination, those only recently treated, or those who felt that their condition was unstable at the time of interview.

4.2 Do you think that telephone consultations have any advantages or disadvantages compared to face-to-face appointments?

Advantages:

- There was unanimous agreement on the benefits of time saved travelling to hospital and dealing with parking difficulties.
- This time saving also means significant reduction in stress and anxiety. This includes difficulties associated with time off work and conflict with caring responsibilities.
- Several people commented on the environmental benefits of reduced car travel.
- Overall, the time savings make the telephone consultation far more time efficient, and people believe that this also means time and resources saved for the NHS. Some people stated that HCPs had been willing to be more flexible and rescheduled phone appointments if necessary.
- Telephone consultations mean reduced risk of contracting COVID-19.

Disadvantages:

- Telephone consultations mean that there can be no physical examination. Many people – particularly those with conditions that are less reliant on blood tests for monitoring purposes – expressed regret at the loss of the reassurance of a physical examination.
- Telephone consultations mean potential losses in terms of successful communication. A telephone consultation can feel more efficient but this can also mean 'too business-like', more a Q&A than a conversation. Social interactions – how are you? Did you have a nice weekend? – are important in putting people at ease and making people feel relaxed. A more conversational approach can better prompt some people to think of things they want to ask or discuss.
- Similarly, it is easier to withhold information over the phone. If someone 'doesn't want to complain' or is reluctant to admit something to themselves, it is easier to paper over the cracks in a phone call.
- It is harder for a spouse, relative or carer to contribute to a phone conversation. Often these are the people who will ensure that the clinician gets the full picture and that appropriate questions are asked.
- Some people pointed out that telephone appointments mean that more than one day is taken up with follow up procedures: people in established follow up routines will often arrange blood tests and pharmacy visits for the day of their follow up appointment so it is all 'done' in one day and they can forget about it until next time.
- In some cases, the emotional tone of the interview suggested that there was more significant regret at the loss of a face-to-face relationship with the care team.
- All participants suggested that there are times when a telephone appointment is not suitable. Many said that the telephone clinic model would not have worked at the early stages of their illness when the importance of physical and face-to-face contact with medical professionals is critical for emotional reassurance and establishment of trust.
- Although people do not miss the journey to the Churchill, there is something about the process of travel to hospital and sitting in the waiting room that makes a person feel more prepared for the consultation. Participants reported feeling less well prepared for a telephone call, and suggested that it helps to write down questions and take note of symptoms or other issues of significance.
- Similarly, the environment of the waiting room helps to explain why an appointment might be delayed. "You can see how busy they are, so you don't worry if it's running late". It is easier to worry that you have been forgotten if the phone call is late.

4.3 Would you feel comfortable with further telephone consultations in future?

- People see telephone clinics as something that is necessary under current circumstances and are more than willing to comply with anything that will keep them safe from contracting the virus. They are happy to comply for reasons of individual safety.
- Other people will say that the switch to telephone calls makes perfect sense regardless of whether it is in response COVID19 ("we were backed into a corner with COVID, but it might be a good corner"). These people are more than happy to carry on with this arrangement in future.
- However, most patients would prefer to know that they can see their clinician face-to-face if necessary. They all conceded for on occasions, and for some patients, telephone calls are not adequate. There are intangible components of care – familiarity, knowledge of

one's history, seeing a person you trust – that enrich a sense of being cared for and are difficult to replicate remotely.
- People really do need to be reassured that face-to-face is an option if they are worried or if they feel they need to see someone in person.

4.4 Would you be interested in a video consultation if it was offered to you?

- The interviewees had mixed opinions on the idea of video consultations. Many cited the technical difficulties with Zoom or Skype as examples of how the technology can let you down and this might make already fraught conversations more stressful. Some suggested that they 'clam up' if talking online. Few people had used Attend Anywhere, but those that had were satisfied with that experience.
- Several people feel far more comfortable with the 'old fashioned' reliability of a phone call.
- Those that expressed an interest in video consultations stated that they liked the idea of seeing someone's face and reading body language and other non-verbal cues.
- Some mentioned that video consultations would give the patient the opportunity to show someone a rash, or a lump.
- People would prefer to be offered a choice between phone and video consultation.

4.5 Do you have any further comments about telephone consultations or our current service?

- Several people talked about the merits of being better prepared for a remote consultation. Although the process of getting to OUH is tiresome, it does at least focus the mind on the task at hand, and this is lost with a phone call. Patients might wish to prepare in advance of the appointment and make a note of points to raise or symptoms to discuss. One person used the example of a diary completed as part of a clinical trial that meant he felt better prepared for consultations with his medical team.
- Some people commented on the need for effective administration to reassure people in the reliability of the service. There are examples of letters arriving that contradict texts or phone calls from our service; this causes confusion and creates the impression that we are wasteful and disorganised. The appointment system needs to be reliable and trustworthy, especially as patients are no-longer responsible for making their own appointments by handing in the 'green form.'
- Timing of the call is very important. Calls being too early or too late cause anxiety and inconvenience.

5. Discussion, challenges and considerations

It is perhaps an obvious statement to make, but a telephone consultation is not the same as a face-to-face appointment. However, it requires the same attention: attention to the call itself and to the system that surrounds it.

Establishment of trust, doing your preparation and the challenge of new patients and HCPs

- Positive experiences are often related to established relationships of trust with professionals that the patient has met in person. **Feeling that that person knows you is critical**; even if the clinician is new to the patient they must take the time to prepare for the appointment and familiarise themselves with the patient's history. Negative

experiences typically take place when a patient feels that the clinician making the call has not prepared and "has no idea who I am". This significantly undermines faith in the safety of telemedicine.

- The division will need to **consider how to cultivate familiarity with patients and HCPs who are new to the service**, with adequate training and supervision for clinicians. It will be important to maximise opportunities to build trust at the onset of a patient's experience with our department to sustain the period when they cannot see us in person.
- Trust is also dependent on a system of information and support, in particular timely and reliable access to the CNS for support between appointments. The physical environment and visits to hospital reassure people that a friendly service is there to help and attend to them; this reassurance is withdrawn with telemed, and we need to reassure patients that it is there and encourage them to take advantage of it if necessary.

The risks of withdrawing face-to-face appointments – or failure to reassure patients about this

- There is consensus among the people that were interviewed that **sometimes face-to-face appointments are necessary**. This might be because of the breaking of bad news, an unstable illness, or the necessity of a complicated and technical conversation such as consent to a stem cell transplant. People can experience significant anxiety at the loss of a physical examination for an indefinite period. Knowing that a face-to-face appointment is an option will sustain faith in the telemed model.

Communication skills

- Speaking on the telephone is not the same as communicating face-to-face. The department should address whether clinical staff need **access to training and resources** to ensure they are prepared for a very different mode of relating to a patient. Good communication skills help to ensure that a consultation over the phone has an opportunity to get to the crucial issues for that patient. This might include skills in **asking the right questions**, involving a spouse or carer, or knowing when a patient might be withholding something significant. **Taking your time**, **checking in** with the patient, and **summing up** a particularly complicated call can also help the person furiously trying to take notes on the other end of the line.
- If the person feels that the call is a conversation rather than a Q&A then they are better able to communicate, recall what they want to say, and ask questions. Clinicians should **take the same time to ask social questions** and engage in 'small talk' in the way that you might if you were seeing the patient in clinic. This sort of interaction puts people at ease and makes people feel like an individual who is noticed.
- Similarly, it is important to pay adequate attention to how you introduce yourself: clear introduction including a title; a reference to whether or not you have met the patient before and if so when this meeting took place. This sort of attention to the details of conversation helps to compensate for what is lost when not seeing someone in person.
- Of course, 'face-to-face' does not mean what it used to mean; at present, facemasks obscure expressions and familiar features. It will be for further work to unpick **the impact of PPE on clinical consultations** and what it costs patients in terms of communication, particularly those who might not have English as a first language, or people who are hard of hearing and rely on lip reading.

Timing and preparation

- Perhaps counterintuitively, the hospital environment can offer reassurances that are absent when you are sitting at home waiting for a call. If your appointment is running late when in the clinic, the busy environment helps to explain the delay because people are busy and there are lots of other patients to see. However, if a telephone call is very late, the patient doesn't know why, and might fear that the appointment has been forgotten – especially as some of the responsibility for making that appointment is out of the patient's hands. Similarly, if a telephone call comes early, it might be inconvenient. One person cited an example of a call that came two hours early, which meant that his wife had to leave a work meeting to join the conversation. **Telephone clinic lists should have the same concern for timing as face-to-face appointments.** The stress of waiting is the same regardless of where you are seated.
- The hospital environment also lends a degree of preparedness on the part of the patient, in that they are in "consultation mode" and have time to think about what will take place. Telephone consultations might be improved with some **more structured preparation on the part of the patient**. This might be simple guidance on what to make a note of, or a reminder to write down questions that need to be asked. Teams in the department might want to consider the preparation of tools for different disease groups to guide effective consultations.

Choice between phone and video

- This study was not designed to test preferences between Attend Anywhere and telephone calls, as many people had not experienced video consultations. Some people felt that it would be good to see someone's face and read non-verbal cues, share things like skin rashes, or look at scans together. However, a significant proportion of interviewees expressed **reservations about video consultations** because of fears about the reliability of signal, sound and image which might complicate an already fraught consultation.
- If the department is to expand the use of Attend Anywhere, we perhaps need to consider reassuring patients about the favourable reception it has had.
- People should be invited to express any preference between the two; many people don't think there is a choice unless it is offered.

What about the relative, spouse or carer?

- Something that this study did not fully address is **the role of significant others**, whose voices are largely absent from these interviews. We know that few patients experience their illness in isolation: it is something that happens to a family, and the people close to the patient are vital to the support network and the communication of information. If we consider that comparatively few face-to-face appointments happen without the presence of a relative or carer, then we need to establish how to include these people in telephone consultations.
- Other people can join Attend Anywhere consultations and this should be made plain to patients as a potential advantage of video over telephone consultations.

Patient portals and blood tests

- The OUH patient portal, which will allow patients access to blood test results, might make telephone consultations more successful for some groups of patients. One patient

commented on how useful it is to know blood test results in advance: it means that the telephone consultation begins from a basis of equal understanding, and can "go straight to the discussion" of the results and their implications. Without this, the blood result must first be communicated to someone who is anxious and the fact of the blood result must be absorbed and noted before the consultation can proceed. **Patient portals will help those patients who choose to use them to engage with their condition** in a way that might contribute to the success of remote consultations.

- Several people commented favourably on the current blood testing arrangements at the Churchill hospital. The system is well managed and convenient and it saves people sitting in the OPD among other people while waiting for a blood test. If telemed is to protect people from viral exposure, then it doesn't make sense to patients that we revert to a location that feels unsafe to them.
- Others who live a long distance from Oxford expressed frustration at not having blood tests carried out nearer to home. It feels like an added risk to their safety to have to venture far afield for something that might easily be carried out at closer proximity.

Are telephone consultations successful? To a certain extent, yes they are. Yes, the conversations that can be had are usually the same as the conversation you might have face-to-face. Yes, telephone consultations save time, stress, money, energy, and the environment. Yes, it is safer to protect people from the virus by keeping patients at home. But this study has highlighted issues that might not be immediately apparent to clinicians. "Care" and "trust" can be fragile entities that rely on a system of interactions. They rely on good administration; on access to appropriate information and the knowledge that back up is there if required. They rely on significant others – carers, spouses – being equally able to contribute to a consultation. And there are significant intangibles associated with the physical proximity of one's HCP: non-verbal communication; emotional reassurance; the pleasure of seeing people that you like and have established a relationship with.

Telephone consultations demand the same respect reserved for a face-to-face appointment in terms of timing, communication and attention to the individual and their family. But done well, with appropriate training for staff, and with the requisite choice and flexibility, they are a popular, important and valuable contribution to the care we offer our patients, and not only during the era of COVID-19.

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