

# COVID-19, NHS England highly specialised services

## Views about the place of videoconference and telephone clinic calls during the pandemic period

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- Aim: To know patient, family and carer views about their experience of a number of outpatient based rare disease clinic care since the start of lockdown on 23<sup>rd</sup> March 2020.
- Lockdown resulted in many services running clinic appointments by telephone or video clinic calls instead of face to face. Urgent and emergency aspects of these services continued to operate and are excluded from this review.
- We would then develop principles to help the NHS England highly specialised commissioning team work with clinicians to transform HSS services and develop a more 'Hospital at Home' style blended offer where appropriate.
- The calls were held on 16<sup>th</sup> and 22<sup>nd</sup> June 2020 with children, young people and adults who access a rare disease service and their families and carers. Also on the calls were the charities who support these services, the clinicians who provide the services and the NHS England highly specialised services commissioning team Fiona Marley, Minal Patel and Bernie Stocks. Questions are shown on Appendix one.
- The rare disease services represented were Alström Syndrome, Ataxia Telangiectasia, Bardet Biedl Syndrome, Wolfram Syndrome and Primary Ciliary Dyskinesia.
- Six adult patients and their families, and eight children and young people/their families joined the calls including two emails from two patients. 14 clinicians and 10 charity representatives of ASUK, The AT Society, PCD Family Support Group, BBS Support UK and WellChild were also present across the two calls.

## What people like about face to face clinics

Physical expert assessment, interaction with other families, 1:1 time with the Clinical nurse specialist/other staff, informal discussions with staff people may feel more able to share questions and concerns, round table discussion with clinicians and other families after the shared lunch.

Assessment of physical, emotional and behavioural problems and pastoral care. Getting to know and be comfortable with the multiple members of the clinical teams. Developing relationships and building Trust with individuals and teams.

## What people have valued

Help from clinical teams, charity teams and voluntary helpers to access care via virtual clinics and to stay well at home. Help in setting up systems and practicing their use prior to a clinic. Translators.

## Comments

‘Coming to hospital is a cross infection risk from other patients anyway, let alone COVID-19’; ‘having a rare disease like this ‘is a way of life not a sickness to be cured as there may not be a cure’...so its about helping people manage the best they can; ‘the patient cohort in each service have different needs and within the cohort, each patient can have different care and support needs’.

What people really want is to know that there is a clean and safe way to get through the hospital, including those patients who have to go in and be admitted. Some are concerned about the new cleaning products that may exacerbate lung conditions.

# Positives of telephone and video clinic appointments

## – slide 1



- Whilst they cannot replace a face to face review, due to COVID-19, some clinicians have already carried out urgent new patient reviews over phone/video call to decide whether the case is urgent enough to need to be seen face to face directly. e.g motor tests, swallowing assessments by speech and language therapists.
- Video clinics mean you can show the patient x-rays and talk through these. 'We started doing telephone clinics but moved to video clinics, which we prefer as you can do a lot of examinations by watching how someone breathes.'
- Multidisciplinary team assessments are happening, including physios, specialist nurses, speech therapists, multiple consultants. 'It was good to see the 8 clinicians in a 3-5 hour call rather than a full day with travel'.
- Calls are really helpful for stable patients to carry out routine follow ups.
- 'Really good' to see the different members of the multidisciplinary team. Some online systems can let one member of the MDT and the patient to go into a separate 'room' to talk about particular aspects of care/issues.
- 'It's a good way to identify immediate issues' including prescribing antibiotics and making onward referrals to other clinicians. Although there are some limitations now, technology enabled assessments will help in the future, e.g with assessment of ears, lungs.
- More family members can attend the calls than would normally travel to clinic.
- District general hospital (DGH) clinicians and GPs are being invited to join some of the calls – which they appreciate as felt were not involved enough in patient care 'can join up better'.

## Positives of telephone and video clinic appointments – slide 2



- Cardiology and renal clinicians have been able to join the calls.
- ‘It is good to see the patient in their home environment as they are more relaxed and say more’
- Before appointment checks - in one case the person’s community nurse was able to do height and weight and other checks. Others went to their GP, although some were too anxious to interact with health staff.
- After the call, one patient was referred to a locally based play therapist.
- ‘The cardiologist did a healthy heart webex for families and the young person took a lot of notice of that’.
- ‘We have been doing video clinics for two years, it works as an interim appointment to keep in touch with the patient and prepare them for the big two-day face to face appointment, but we see variation in the patient group and it doesn’t work for everyone’.
- A videocall was carried out with an interpreter present.
- Patient hearing aids can be linked to their computer so that they can hear the clinical teams.
- ‘Having a check-in on the phone is good, it shows you are still on the radar and for long term patient who are not presenting with problems – its good for them’ noted a parent.

# Concerns with telephone and video clinic appointments

## - slide 1



- Video calls are reliant on people having sight and/or hearing and/or neurological ability to access the web link – in some cases a telephone call is better.
- There may be cultural issues for individual patients which need to be taken account of.
- ‘In a face to face clinic, you get the chance to speak to the young person on their own to see how they are – that is not possible on a call as other family members will be present’, ‘Its difficult to judge the mood of a patient over the phone, much easier when face to face’, ‘Face to face, there is space for children to run around whilst the parents can talk and have head space and talk informally to the nursing and support staff – that is missing’.
- ‘You can’t replace hands on assessment’ such listen to the chest, check eyesight and technology enabled assessments such as MRIs’, CT, X-Ray for heart, liver, kidneys etc. ‘These are really important and still need to happen’. Therapy assessments have taken place but are more limited.
- In the face to face clinics, a young reluctant communicator was seeing the dietician on her own enabled by visual signals, but is not comfortable speaking on the phone calls.
- Charity teams and clinic support staff provide social and coping-based support advice to schools and local carers to help the person, including how to get groceries. Some families feel less able to ask for that sort of help over the phone.
- Transition clinics can still take place over the phone/video but young people ‘still need to see the new clinical team and unit face to face so that they can get used to the layout’ as it’s a big change.
- Clinical deterioration can be gradual – that can be difficult to pick up over the phone or a videocall.
- Human to human interaction is ‘different’ over the phone/virtually. Its more ‘impersonal’
- Blood tests need to be recent to be relevant to clinical discussions.

## Concerns with telephone and video clinic appointments - slide 2



- ‘Clinic reviews are like an annual health check. Its difficult to do that remotely, recent blood tests such as blood glucose are needed to be meaningful’.
- Local teams don’t have the experience and expertise to manage these patients and need to take the lead from the rare disease services ‘the local team tried to change her hearing aid and shouldn’t have’.
- There is unequal access to testing in primary care and in local hospitals – some patients struggle to get a GP appointment ‘in the next three weeks’.
- Some patients with visual and hearing loss have refused a phone/video call with the clinical team as they felt it wouldn’t be beneficial to them, preferring to wait to be seen face to face.
- Some patients have barriers to accessing services, such as language, can’t use or don’t have IT, domestic control issues.
- Some rare disease conditions don’t have treatments, so research based on detailed observations with the patient in front of you is vital to inform developments.
- ‘We cannot use the current technologies and [virtual clinic] approaches as a benchmark for a future model of care business case to proceed. Patients need more education in these emerging technologies and possibilities.
- Patients should be given the option to have a face to face clinic appointment or phone/video clinic appointment – not either/or.
- ‘The worry is that that patients self select that they are seen virtually instead of coming to clinic, so avoiding a full clinical review. This needs to be a doctor-led approach.

# Transformation opportunities slide 1

- Provide help for patients and their families/carers to get the most out of the virtual appointments by helping them to prepare beforehand by: i) writing out a list of questions and queries ii) fill in the virtual clinic 'top ten' style checklist iii) check out the top tips for having a good call (no other noises etc).
- 'Hospital at Home' minor testing. As an example, home spirometry (remote lung function testing) for patients of the PCD management service has just approved and is in place for a 12 months trial. Other HSS rare disease services have been asked for a list of minor testing equipment that may inform consultations.
- Technology enabled remote testing i.e ophthalmic tests, and more use of DGH and local trained clinicians (? high street opticians).
- Organising for key diagnostic tests to be done locally in advance of rare disease appointments such as bloods tests and blood pressure, review of insulin pumps etc. Some larger hospitals have roving blood testing available.
- Care co-ordination of tests and preparation for clinics and ongoing care essential. Some patients need a lot of tests on a regular basis and can't do the care co-ordination for these to happen locally and making sure the results get to the rare disease service as some patients/families are not able to manage this.



# Transformation opportunities slide 2

- Software: some hospital software systems enable videocalls to be captured and retained on the patient record, some have a virtual waiting room and multiple clinic 'rooms' with different clinicians waiting to see the patient, thus enabling the child/young person and their parents to be seen at the same time to discuss their case. Multiple phone call slots also achieve this.
- Software: need integrated, compatible hospital and primary information systems which can 'talk' with one another.
- Having GP and or paediatrician or DGH clinical team on the multidisciplinary team calls for care continuity.
- Local teams need to take direction from the rare disease services on the management plan.
- Pastoral care and education for families to manage at home, such as via informal chit-chat sessions and educational webexes to support patients and connect families with each other and clinical/family support staff.

# After this work

- A number of successful business cases were developed and submitted to NHS England specialised services senior management team to access national COVID-19 monies.
- These aimed to provide home testing equipment to patients at home so that they could take measurements at home to be used as part of video clinic appointments.

# Appendix 1: List of Questions

1. What do you like about the way your rare disease service clinic appointment normally works and what of this do you miss?
2. How has your specialised rare disease service delivered care to you during the COVID-19 pandemic period - have you had a telephone clinic or a telemedicine appointment?
3. How did your appointment compare to the normal 'face-to-face' appointments?
4. What worked well?
5. What didn't work so well?
6. Before your appointment, did you have to go to your GP or local hospital to have any tests done?
7. What aspect of this new way of working would you like to keep in place for the next six months or longer whilst Covid-19 is still around?
8. If you have not had a telemedicine clinic yet, do you think this is something you would find helpful and why? Do you have any concerns?
9. What changes to the service would you like to keep in future?
10. Have you received support or care from the rare disease service in other ways, such as telephone calls, letters, information?

# Appendix Two: List of participants

## **Clinicians from the services**

### **Staff from the participating charities**

The AT Society

ASUK

BBS Support Group

PCD Family Support Group

WellChild

Wolfram Syndrome UK

## **NHS England highly specialised services commissioning team**

with thanks to the people who use the services and their families for participating