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Virtual clinics in Highly Specialised Services (HSS): guidance for services supporting patients with rare and complex and multi-system disorders

Lessons learned from the COVID-19 pandemic

7 March 2023

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Introduction

1.1 Background

People with rare and complex multi-system disorders and their families or carers may struggle to travel to face-to-face hospital appointments with the frequency required. Following the changes that the NHS had to put in place to continue to provide clinical care through the COVID-19 pandemic, most acute trusts implemented video call software for digital/virtual clinic appointments. Depending on a patient's clinical need, there is now less need to travel to expert centres for routine follow up assessment and care planning, as specialist teams can connect with them at home.

About this document

The aim is to provide acute hospital teams with guidance when setting up or improving the safety and efficiency of already established digital/virtual and phone clinics.

It contains:
- a chapter for each of 14 principles to guide provision of virtual clinics;
- worked examples gained from clinical lessons learned;
- a gap analysis and implementation planning template for acute Trust teams to use when implementing virtual clinics or in their action planning to improve the safety and efficiency of virtual clinics they currently provide. See Appendix 1.

It is based on lessons learned during the COVID-19 pandemic gained in providing digital/phone clinics for the follow up of stable patients with rare, complex and multi-system disorders.

Contributors were:
- multi-disciplinary clinical team (MDT) members from national NHS England Highly Specialised Services (HSS) which support patients with rare, complex and multi-system disorders,
- staff in the charity teams which support patients in these services.

See Appendix 2.

Some of the tips and lessons learned in this guidance document may also be useful to acute trust teams who may occasionally need to triage new patients/service users using virtual appointments.

The word patient(s) will be used instead of person or service user in this document.

The term 'virtual' clinic appointments will be used instead of digital in this document.

About NHS England Highly Specialised Services (HSS)

HSS are services commissioned at a national level for patients and service users with rare, complex and multi-system disorders who need regular expert assessment, monitoring and treatment to stay as well as possible. HSS are for rare diseases, typically have no more than 500 people with the condition and are delivered nationally through a small number of centres of excellence.

Examples of highly specialised services include the Open fetal surgery to treat fetuses with open spina bifida service, Retinoblastoma service and Bardet Biedl syndrome service. See also https://www.england.nhs.uk/commissioning/spec-services/highly-spec-services/

1.2 How the COVID-19 pandemic acted as a catalyst for adopting the virtual care model

In March 2020 at the start of the COVID-19 pandemic, virtual clinic and telephone appointments needed to be made available at scale across the NHS, providing an alternative to face-to-face clinic appointments for many patients requiring non-urgent appointments.

The ability to offer virtual clinic appointments enables health service staff to monitor patients at home and reduced the need for large numbers of vulnerable patients to travel into hospitals.

Three years on, virtual clinics are now well established in many services. There are however, extra considerations that care providers need to take into account when providing virtual clinics including that patients have individual levels of need. In some cases, face to face assessment will always be necessary.

1.3 How this guidance was developed

This guidance is based on the NHS England (NHSE) HSS Digital Strategy which was created in 2020 just after the widespread introduction of video calls in HSS, implemented as a result of the start of the COVID-19 pandemic. Engagement calls were undertaken in March, April and May 2020 between HSS multi-disciplinary (MDT) clinicians; patients, their families and carers; charity staff who support these services and NHSE HSS commissioners. Delegates shared examples of their lived experiences of providing or receiving HSS care virtually during the early days of the COVID-19 pandemic.

Delegates also shared the difficulties they had experienced such as diagnostic and assessment gaps; and there was learning of what to do to try to ensure virtual clinic appointments match the face-to-face clinic experience far as possible.
The aim of the engagement calls was both to listen to clinical, patient and charity staff challenges but also for clinical teams to rapidly share learning among participants.

Due to the exceptional circumstances of the pandemic, some HSS submitted business cases to NHSE HSS commissioners for COVID-19 pilot monies to provide patients with home blood testing and small pieces of home testing equipment to test blood glucose levels, height and weight, body mass index and waist measurements. The intention behind the business cases was that patients would regularly take the tests at home and share their data with their HSS clinical team to help them make more informed decisions in virtual clinic appointments. These data would also enable clinical teams to monitor patients between appointments.

The impact of these measurements on clinical practice is being evaluated; feedback includes that home testing data is extremely beneficial as part of the overall monitoring of patients.

In 2020, 13 HSS services on 31 hospital sites benefitted from funding for home testing equipment and six services on 17 hospital sites benefitted from access to the home blood test kit service supplied by the Royal Devon and Exeter NHS Trust's home bloods service. Two other services proposed to set up their own Trust-run home blood testing services, one of which progressed. For the list of equipment items, see Appendix 3.

1.4 Types of challenges faced

There are advantages and disadvantages of whether a virtual clinic appointment is right for a patient.

In the early days of the COVID-19 pandemic, changing to virtual clinics was essential due to isolation rules and infection controls, and this learning enabled all Trusts to set up the technology and processes needed.

Some HSS teams are keen to continue with a hybrid or 'blended' mix of face-to-face appointments and virtual calls.

Advantages of virtual clinics include:

- Reduced cost of travel for patients and their families – both in financial terms and time off work/school.
- The likelihood of a patient accessing a virtual appointment may be greater than them attending a face-to-face clinic appointment.
- MDT staff such as consultants, specialist nurses and psychology staff who speak with patients periodically found it beneficial to organise calls with patients between clinic appointments to find out if extra support or extra local testing is needed and to determine if the patient needs to be fast-tracked to the HSS clinic to be seen face to face.
- Reduced NHS carbon footprint.

Care is needed though to ensure that virtual appointments do not increase inequality of access for those patients with poor broadband coverage or without a smartphone or laptop.

Potential drawbacks of virtual clinics which need to be considered include:

- If there is a likelihood of a need for a physical test, this will have to be arranged separately.
- Access for those patients with poor broadband coverage or those without a smartphone or laptop.
- Different Trusts use different IT systems for their virtual appointments which may require patients to access and become familiar with the multiple different IT systems which may be being used.

1.5 How this guidance contributes to the delivery of the UK Government's Rare Disease Framework

This guidance will support acute trust providers in delivering Priorities 3 and 4 of the UK Government's Rare Disease Framework (RDF) and contribute to meeting improvements in patient care as set out in the RDF's Digital, data and technology underpinning theme as shown below:

UK Government's Rare Disease Framework

Priorities:	**Underpinning themes:**
1: Helping patient get a final diagnosis faster	Patient voice
2. Increasing awareness of rare disease among healthcare professionals	National and international collaboration
3. Better coordination of care	Pioneering research
4. Improving access to specialist care, treatment and drugs	Digital, data and technology
	Wider policy alignment

Principle 1: Be accessible

This principle asks acute trust teams to consider 'digital poverty,' that is the physical or geographical access barriers for people who are accessing some elements of a service virtually.

Why is this a principle? In the engagement sessions, HSS MDT clinicians noted that teams need to be aware of the barriers to equitable access to virtual clinics for patients and their families or carers. Virtual clinic appointments on phones and laptops can be data hungry and may use up excessive amounts of payment plans.

What should Trusts do?

Actions for acute trusts to consider:

- Check whether the patient/their parents/carers are able/unable to access telephone or video appointments due to cost or IT issues or if they have physical constraints such as visual impairment.
- Where clinically appropriate, patients should have the option of virtual or telephone follow up outpatient appointments as well as face to face appointments and telephone calls. It may be clinically necessary for there to be a 'blended' model of virtual and face to face appointments.
- Stratify patients based on their clinical need. Those who have been diagnosed as having low levels of need may be interested in piloting the use of virtual calls.
- Offer choice of format for outpatient follow-up appointments: (where appropriate, consider whether telephone or videoconference follow up appointments suit patient needs and the frequency of these including an alternating pattern with face-to-face appointments).
- See if the Trust has a digital champion who can assist patients with accessibility issues or literacy and language barriers to join video clinics.

"It was good to chat on Zoom, like being in the same room as them, we felt at ease chatting…" parent of child with Ataxia Telangiectasia

Key resources:

The NHS Digital inclusion Guide (https://www.goodthingsfoundation.org/sites/default/files/personas_no_support.pdf) is for use by NHS staff to support patients to access digital care including virtual clinics. Blocks to access can include:

- patients or their families not having a laptop or tablet or smart phone;
- lack of interest in using IT,
- lack of up-to-date digital skills or familiarity with using technological devices;

- poor IT connectivity;
- physical accessibility issues;
- physiological difficulties such as neurological deficit;
- visual or hearing issues or language barriers and/or low income.

Staff across health and social care can be trained as Digital Ambassadors. Health Education England offers Topol Programme Digital Fellowships: see https://www.hee.nhs.uk/our-work/topol-review

Principle 1: Be accessible - Worked example from spring 2021

Ataxia telangiectasia service (children): The A-T Society has been providing short online and telephone lessons for parents and adults who have A-T, on how to use the Zoom online tool before a clinic appointment to help people get used to the system and gain confidence in using it. Some families have expressed an interest in having virtual clinic appointments to save having to travel to the clinic for an interim assessment if their child is stable.

Multiple sclerosis management service for children service: The service is planning to offer telephone clinic/virtual consultations for routine follow-up appointments.

Retinoblastoma service: Whilst some patients need to be seen in person, school visits and appointments for patients with lower levels of need can be done virtually.

Vein of Galen Malformation Service: Parents have benefitted from being able to send messages directly to the service's clinical nurse specialist (CNS) via the Trust's electronic patient record (EPR) system (EPIC) These are saved in the patient record.

> "The service has used a blended telemedicine approach for some time, so when the COVID-19 pandemic occurred, clinical teams were ready to hit the ground running with providing video clinics, although these are harder to access for patients with hearing, visual or dual loss to access and more effort in advance is needed to facilitate these e.g. two screens, larger text…" clinician, Bardet Biedl Syndrome service

Principle 2: Be flexible

This principle asks acute trust teams to consider options for local testing; diagnostics, monitoring and medicines at home or in primary care; in new diagnostic hubs; and local hospital units as well as in national HSS units.

Why is this a principle?

The HSS clinicians found in the pandemic that if patients were able to access tests such as ECG or blood tests locally, and share the test outcomes with the HSS clinical team before the appointment, this gave the key information needed about the patient's progress and reduced the time needed for the HSS clinic appointment.

Funding was also made available during the COVID-19 pandemic by the national specialised commissioning team for a pilot to fund small items of testing and monitoring equipment. These were sent to patients at home to test key parameters and the results were used in the next virtual clinic appointment.

Equipment purchased by Trusts included spirometers, urine analysis test kits, blood pressure monitors, weighing scales, continuous glucose monitoring machines and home blood tests using capillary sample kits. Some families were also able to have bloods taken locally, before they attended a clinic.

What should Trusts do?

Actions for acute trusts to consider:

- Have a named care co-ordinator in the service so that all parts of the system can connect with the service's management plan for the patient including latest test results.
- Modify patient monitoring regimens by reviewing what is essential for the virtual call and what can be scheduled for the next face to face appointment.
- Pilot home or local testing and monitoring subject to finances and planned benefits.

Principle 2: Be flexible – worked example from Spring 2021

Primary ciliary dyskinesia management service for children: The clinical team say vulnerable patients, many who are vulnerable to infection, have reported high levels of satisfaction in being to test themselves at home and report the results to the HSS team.

'It has been good to give remote monitoring equipment to patients to use at home as it has highlighted the discrepancy between what used to happen in access to spirometry testing. To a large extent this is now equal, and we can get comparable measurements during follow up clinics and with clinicians in network units…'clinician Primary ciliary dyskinesia management service (children)

Principle 3: Be informed

This principle asks acute trust teams to consider widening the membership of the MDT to include members of relevant regional specialty clinics and local clinicians who are managing a patient's care.

Why is this a principle?

Wider representation of the MDT will support more informed MDT discussions, enable local teams to understand better how to manage the condition and support the patient's care local. It can also improve communication between local clinicians who are managing the patient and ensure that parents, school nursing teams and social workers can all be part of discussions.

Outreach clinics before the pandemic were carried out in person and during it were done virtually. Some HSS clinicians found it very helpful to have wider MDT discussions before the patient joined the call and then again once the patient left to plan next steps in more detail.

During the pandemic, some MDTs were expanded to include key local staff such as pharmacists, paediatricians and tertiary or secondary care consultants who manage the patient's care locally. Previously long travel times could have prevented them from joining the meetings.

What should Trusts do?

Actions for acute trusts to consider:

- Identify other key local clinicians or teams who are involved with the patient's ongoing care and should be included as part of discussions/decision-making.
- Creating multiple virtual clinic 'rooms' in virtual clinics, with patients and families/carers rotating through the MDT members in timed appointments so that they can still benefit from MDT review.

Principle 3: Be informed – worked examples from Spring 2021

Bardet Biedl syndrome service: Enhanced MDTs were used as an opportunity to co-ordinate care and to discuss with local teams as well as with other MDT's.

Bardet Biedl syndrome service, BBS UK (charity): The charity staff met with patients and their families before and after the clinics (whether virtual or face to face) to talk through any concerns or questions they may have had and to hear their feedback on the appointment.

Primary ciliary dyskinesia management service for children: The clinical team were able to bring together MDT specialists such as cardiology, ENT and dieticians who were local to the patient and supporting them close to where they live.

'Although joint MDTs are normal, in the COVID-19 pandemic period, these were extended with radiological data shared with multi-disciplinary professionals in local units during discussions on starting their patients on treatments'…clinician, Complex neurofibromatosis Type 1 service

Principle 4: Be present

This principle asks acute trust teams to ensure that patients and families/cares follow the virtual clinic planning guidance provided by the clinical team including: ‘Be ready, be timely, be present; be charged up and ready to go; Think small’.

Why is this a principle?

At the beginning of the pandemic, there was relatively little understanding of how to ensure the best outcomes from virtual calls. It quickly became apparent to clinical teams and the charities that support patients and their families that patients needed to be well prepared for the appointment and to keep distractions to a minimum so that the patient could be heard and for all attendees to ask questions.

Clinicians and charities have provided top tips to patients and their families or carers on how best to prepare for a virtual appointment. These are:

Be ready

The patient and their parents or care need to have dialled into the virtual call a few minutes early and have a list of any questions they have been preparing over a week or so prior to the call.

Be timely

Some families have been allocated a timed virtual clinic slot but are concerned if there is a long delay to the appointment starting whilst the medical teams finish speaking with another patient. If there is a delay, the clinical team need to notify families so that they can get on with other things at home whilst waiting.

Be present

Ensure that the patient together with their parents or carer(s) are in the room for the appointment. If the patient is elsewhere such as at school, the clinical team will not be able to check for current symptoms or complications, hear about issues or undertake safeguarding checks. When the patient isn’t present, the appointment will be cancelled and the appointment rescheduled. Another concern is that even when the patient is in the room, if parents or other members try to dominate the conversation, the clinical interaction with the child/young person will be compromised.

If the condition has physical symptoms, some HSS teams found it helpful during the pandemic to ask parents to film a short video on their phone of the child going about their normal activities such as walking. If this is sent into the clinical team in advance, teams can view how the patient is affected, Trust Information governance approvals permitting.

Be charged up and ready to go

- Make sure that any phones or laptops to be used are charged up.
- Make sure there is credit on the account if the phone is Pay As You Go.
- Sit in a quiet room to take the call if possible, away from interruptions.
- In the week beforehand, write out any questions you might want to ask.

Think small

Clinical teams need to be able to hear the patient so that they can answer questions and take a view of the patient's condition. Distractions should be removed as far as possible so that the patient and their parents/carers feel as much a part of appointment they would in a face-to-face appointment. Where the patient is a small child or if young siblings or pets are also present, clinical teams have found it helpful for the parents to have books, paper and crayons to hand and snacks to help keep the attention of babies and children.

Good practice suggestions are included on the BBS UK website, where there is an information sheet detailing and top tips list. The link for the information prepared for the adult Bardet Biedl syndrome clinic, which may be useful for other services too, is https://bbsuk.org.uk/bbs-clinics-overview/adults-clinic-2/. The link for the information for the children's clinic is https://bbsuk.org.uk/bbs-clinics-overview/childrens-clinic-2/

What should Trusts do?

Actions for acute trusts to consider:

- Prepare a leaflet for patients and families on how to prepare for the call so they can get the most out of it. This includes the patient being there to join the call if they are a child as well as their parents or carers, in the week before the call write a list of any questions to ask the clinical team during it, being ready in good time to take the call, make sure the phone or laptop is connected and charged up; occupy small children with toys and books and a drink or snack.
- Check if a pre-arranged movement or functional video of the patient would assist with the assessment. Parents/carers can record it and send it to the clinical team in advance of the virtual appointment. Trust IG rules permitting.
- Having a clinical co-ordinator to oversee the running of virtual clinics will ensure that appointments run to time as far as possible.

Principle 5: Be safe and governed

This principle asks acute trust teams to consider how to improve safeguarding in virtual clinics, safely manage complex cases and to bolster clinical governance processes.

Why is this a principle?

With virtual clinics, there are additional privacy and safeguarding concerns which need to be taken into account where the patients are children or adolescents or are older, or are vulnerable such as patients with hearing deficit, learning difficulties, looked after children or patients in assisted living or care homes.

What should Trusts do?

Actions for acute trusts to consider:

- Put in place additional governance measures to reduce risks including working with other staff in the patient's health and care network.
- Agree the frequency of /when virtual appointments where patients can be seen in their home environment and where they may be more at ease as compared to face-to-face appointments – this will be patient specific.
- Invite shared care partners to work with you on the patient's care plan.
- Update standard operating processes and procedures to include additional checks and safeguards across clinical pathways This may include bolstering arrangements with shared care partners to make sure that care is delivered consistently across service hub and spokes.

Principle 5: Be safe and governed – worked examples from Spring 2021

Bardet Biedl Syndrome service: The service has set up a hybrid care model, including seeing patients face to face where possible, to ensure careful safeguarding for children, the elderly, those with learning difficulties and those patients in care homes where privacy is an issue.

Principle 5: Be safe and governed – worked examples from Spring 2021

Congenital hyperinsulinism service for children: The teams ensure appropriate clinical governance across the care network to make sure that patient care is delivered consistently across hubs and spokes. An example of this is the CHI special interest group, which includes representation from England, Scotland, Wales and Northern Ireland and works closely with the UK CHI patient charity. The group has developed a uniform set of multidisciplinary guidelines to standardise access to CHI services, diagnostic procedures and therapeutic pathways based on current best evidence.

> "There is a safety issue that we need to bolster the clinical governance of the care network to make sure that care is delivered consistently across hubs and spokes…"
> clinician, Congenital Hyperinsulinism service for children

Principle 6: Be a listening team

This principle asks acute trust teams to give the patient the opportunity to speak and raise any questions/issues, as well as listening to parents or carers who may also be in the room and who may want to lead the conversation.

Why is this a principle?

Some young people and adult patients have mentioned they felt conscious of other parents or carers or other family members being present and did not feel able to speak on matters that were confidential to them.

If a parent or carer is present on the virtual call and asks or answers all questions instead of encouraging or allowing the patient to speak, clinical staff may have to repeat the question, directing it to the patient and waiting for their response.

Some HSS transition co-ordinators have needed to arrange a second call to speak directly with adolescent patients in the same way as they would in a face-to-face clinic. These staff have noted that some young people feel more able to speak freely when their parents are not present whilst others prefer virtual appointments compared to a face-to-face appointment as they can speak more openly.

What should Trusts do?

Actions for acute trusts to consider:

- Make sure the patient has an opportunity to ask questions and talk to the clinical team even if parents/carers have already asked or answered the team’s questions. This will ensure that the patient is heard, describe how they feel, discuss any symptoms and freely ask any questions they may have.
- Transition co-ordinators may need to schedule another time to speak to the patient alone if they don’t get the chance to ask their questions or have the opportunity for the in-depth chat needed because other parents or carers or other family members spoke or were present.

Principle 6: Be a listening team – worked example from Spring 2021
Multiple sclerosis management service for children: The clinical team found that it was sometimes difficult for families to find a quiet place to join consultations. Appointments needed to be scheduled around the needs of patients in video call clinic rooms.

Principle 7: Be equitable

This principle asks acute trust teams to promote health equality, not worsen health inequalities when offering virtual clinic appointments.

Why is this a principle?

HSS teams have identified that IT issues like IT knowledge barriers, poor internet bandwidth which can impair the quality of calls and that patients and/or their parents or carers may have a cognitive; visual; hearing or neurological impairment, which means they may struggle to manage or communicate on a virtual clinic appointment.

What should Trusts do?

Actions for acute trusts to consider:

- Be aware that some patients may be affected by health inequalities which means they may not have the resources including funds to enable them to join virtual appointments often or at all.
- Identify those patients or paediatric patients with parents or carers who have cognitive, neurological, sight or hearing problems and who may struggle to manage or communicate on virtual appointments. These may need extra support from staff or charities working with the service.
- Invite interpreter services to join virtual clinic appointments where needed.
- The acute trust team should monitor the impact and uptake of offering more virtual clinic appointments to ensure that this does not inadvertently create or widen existing health inequalities. Monitor 'Do Not Attend' and patient cancellation rates. Carry out patient questionnaires/surveys and liaise with charities and stakeholder groups.

Principle 7: Be equitable – worked examples from Spring 2021

Primary ciliary dyskinesia management service (children): For children with PCD there will be at least one face-to-face appointment for an annual assessment, and the mode of all other appointments will be determined by the PCD team and the patient and parent's or carer's clinical needs.

For virtual appointments the clinical team should ask that the patient or their parents or carers have access to suitable devices [smart phones, iPads or computers] and to prepare any questions in advance, ready to raise with the clinical team.
Patients or their parents or carers need to ensure that they have put enough credit on their phones before the call.

Principle 7: Be equitable – worked examples from Spring 2021 - continued

Post pandemic, in addition to having the option for a virtual clinic appointment, most patients either wish to be seen face-to-face or have been advised to attend appointments in person for clinical reasons. There is a clinical decision-making pathway, based on health status, safeguarding issues and additional reviews in the appointment such as hands-on physio or nebuliser trials that dictates whether patients can be offered a virtual call.

‘Inequity had improved as the virtual model has allowed clinical teams to see patients that previously patients would have been deterred by long-travel times, expense or general difficulty in travelling…’ clinician, NF2-Schwannomatosis service

Principle 8: Be compassionate

This principle asks acute trust teams to consider the best ways to break difficult news when there are difficulties for patients to travel to clinic.

Why is this a principle?

HSS clinicians identified at the height of the pandemic that patients could be triaged into those who were ‘stable’, to be seen virtually and those who had more urgent or severe health issues who needed to be seen in a face-to-face appointment.

The benefit of seeing patients face-to-face for the first time is important to build up a rapport and carry out a full assessment before moving on to a virtual appointment for follow-up reviews if appropriate. One clinician noted they found that virtual appointments need to be longer than a face-to-face appointment to enable the patient to become relaxed and discuss any health concerns more freely.

HSS clinicians noted that the general clinical principle is not to break bad news such as a diagnosis on virtual/video clinic appointments as the clinical team cannot support the patient/parent/care in the same way as in a face-to-face appointment. If such news needs to be delivered in a virtual appointment, it should shortly be followed with a planned face-to-face appointment to enable the patient and their parents or carers or other family members to organise their thoughts and questions and make the most of their face-to-face clinic appointment.

What should Trusts do?

Actions for acute trusts to consider:

- Agree the process to deliver significant news such as a diagnosis in a virtual consultation, as it is challenging for clinical teams to provide patients and their families/carers with support.
- Ensure the patient has a supporter with them for the call.
- Quickly follow up with a face to face appointment to allow the patient/parents/carers to organise their thoughts and questions and make the most of the face-to-face appointment.

Principle 8: Be compassionate - worked example from Spring 2021

Craniofacial service: The clinical team say that if difficult news has to be communicated on a virtual call for any reason, they make sure in advance that patients /parents or carers have made arrangements for other family members or friends to be there to support them. The service's specialist nurses will book a follow-on call with the patient's parents or carers within a few days to answer questions, give support and make sure the conversation was fully understood.

Principle 9: Be co-ordinated and share patient management and care plans

This principle asks acute trust teams to clarify who is co-ordinating each element of the patient's care plan through written shared care agreements and communicate these to key clinical staff in the patient's network of care.

Why is this a principle?

Feedback from HSS teams is that most secondary/tertiary care clinicians such as paediatricians who are managing a patient's care close to their home need information and support to do this optimally. Joint management and care plans are key to ensure clarity in care responsibilities of all teams across the care pathway.

Key resources:

The importance of care co-ordination is set out in the Rare Disease Framework: https://www.gov.uk/government/publications/uk-rare-diseases-framework/the-uk-rare-diseases-framework

NHSE providers of rare disease services are required to implement the three deliverables of the NHS 'Rare Disease Insert' where these apply: managed patient transition; care co-ordination via a named care co-ordinator and the provision to patients of a hand held alert cards/rare disease passport.

What should Trusts do?

Actions for acute trusts to consider:

- Clarify which elements of the patient's future care the HSS clinical team will provide and those which the tertiary, secondary and primary care teams will need to provide.
- Written shared care agreements and care plans reinforce the care plan and should be shared with the patient and their GP as well as local and regional hospital staff caring for the patient. This can a 'steps to take' list for regular check-ups that local teams can carry out such as blood tests, weight and height checks.

Actions for acute trusts to consider - continued:

- Communication to local teams via clinic summary letters should be effective and timely.
- Ensure that a specialist nurse or CNS in the service is available to co-ordinate care with local clinical teams.
- Hold MDT meetings and invite the local team clinicians and the GP to join for the section involving their patient.

Principle 9 Be co-ordinated and share patient management and care plans - worked examples from Spring 2021

Ataxia telangiectasia service (children) (AT):
Patients with AT typically have multiple symptoms and the management of the majority of their care needs is provided locally by primary and secondary care teams. The AT service provides information and support to local clinicians to provide local care to patients and supports parents.

Choriocarcinoma/Gestational trophoblastic disease service: Patients are advised by the CNS before they attend the HSS clinic for the first cycle of treatment that they will then return to local secondary care services to receive the remaining cycles. The service identifies key staff in the local teams to co-ordinate local care.

Complex congenital osteogenesis imperfecta service: The CNS writes the care plans and ongoing [drug treatment] agreements and undertakes virtual communications with secondary care hospital teams.

Complex neurofibromatosis Type 1 service: The service has adapted to the new virtual clinic offer as well as face to face and telephone appointments; it has also found the inclusion of other multiple people into MDTs very helpful and efficient.

NF2-Schwannomatosis service: The service holds detailed MDTs annually with each patient’s GP and in some cases the patient joins these. Shared care management plans are shared with the MDT. Liaison across the patient’s care pathway is carried out by the CNS.

“All early conversations with patient and referring clinicians are virtual. More time is made to create rapport and provide emotional support. Service provides co-ordinated care for the whole pathway even when the patient has delivered. Patients report a very favourable experience of the service’s single point of access…” clinician, Open pre-natal surgery to treat fetuses with open spina bifida service

“It has been helpful to have the secondary care/local paediatricians on the joint call for joint consultations…” clinician, Vein of Galen malformation service

Principle 10: Be prepared

This principle asks acute trust teams to add emergency management escalation plans information to existing hand-held Patient-held Alert Cards.

Why is this a principle?

In the pandemic it became necessary for HSS to provide emergency management escalation plans to some patients as well as their patient-held 'alert cards' or rare disease 'patient passports' where they were at risk of deterioration. These would provide emergency departments and acute care staff with next steps actions if the patient presented to a hospital in a clinical emergency.

What should Trusts do?

Actions for acute trusts to consider:

- All patients with a rare disease should already have a hand-held Alert Card created for them by their HSS team so that it can be used by the receiving clinical team in an emergency situation.
- Add to the Alert Card key information about how care should be escalated if the patient's condition deteriorates and they present in an emergency.

Principle 10: Be prepared - worked example from Spring 2021

Open Pre-Natal Surgery to treat fetuses with open spina bifida: Following surgery, which takes place before 25+6 weeks gestation, patients are given both a hand-held and electronic version of their post-surgery care plan to be used in any discussions with local clinicians prior to the planned, local birth by c-section.

"If patients who are being managed by the national service have neurofibromas that may be malignant, they are given a credit card sized card to carry with the HELP* acronyms to help them and any local clinicians to watch for symptoms and contains a contact number for the national service in case of any queries or issues…" clinician, Complex Neurofibromatosis Type 1 service (* HELP stands for Hard, Enlarging, Limb weakness or numbness, Pain, also swallowing, sphincter or breathing issues associated with neurofibroma)

Principle 11: Be collaborative

This principle asks acute trust teams to consider ways to collaborate more with leads across NHS pathways, social care, charity and education teams.

Why is this a principle?

Prior to the pandemic, charity support teams attended HSS clinics in some services to provide support to patients and their parents/carers. Due to infection controls, patients received this support through virtual clinic appointments with charity staff, before or after the main clinical appointment or both.

Decision making and care planning discussions may be more productive if they include other organisations in the patient's care network such as schools, further education and social care teams.

What should Trusts do?

Actions for acute trusts to consider:

- Engage other NHS, charity, education and social care teams in collaborative discussions to improve communication and agree next steps in a patient's care.

Principle 11: Be Collaborative - worked examples from Spring 2021

Alström Syndrome UK, Bardet Biedl Syndrome UK, Wolfram Syndrome UK: Charity teams attended clinics prior to the pandemic to support patients and families in collaboration with HSS medical teams. They now also support virtual clinics in separate 'virtual' clinic rooms so that families can ask questions and receive information and support.

BBSUK: The charity sends patients its 'Top Tips' for video clinic document along with the clinic information and the web link to dial into two weeks in advance of the appointment. This includes sending information by post such as letters, maps and reports for parents or those who are assisting them getting to the appointment as some are visually impaired.

Principle 12: Be innovative

This principle asks acute trust teams to consider making changes to people, process/system and technology functions within the care pathway to increase the successful implementation of these as part of virtual clinics. This includes planning to adopt new technological systems; digital tools; increased use of artificial intelligence (AI), big data and machine learning to improve the use of data in clinical practice and to maximise use from existing systems such as clinical registries.

Why is this a principle?

In the pandemic, staff in HSS took on the role in March 2020 to convert face-to-face clinics to virtual clinics for non-urgent care, although not all processes and systems were in place at the start to help staff do this as effectively as possible.

Trust teams needed to consider people, process, system and technology functions involved in providing virtual clinics.

Key resources:

The NHS Long Term Plan https://www.longtermplan.nhs.uk/ aims to improve access to virtual clinics for patients (section 4.38) and expand multi-professional credentialing to enable clinicians to develop new capabilities and for these to be formally recognised in specific areas of competence.

What should Trusts do?

Actions for acute trusts to consider:
People:

- Review whether administration and nursing support to virtual clinics can be standardised in job roles by expanding scope of practice;

Process:

- Ensure there are appropriate data flows to clinical registries to inform best practice, including what elements of care can appropriately be managed in virtual clinics;
- Align practice to new innovations such as the seven Genomic Medicine Alliances which deliver genomic testing to rare disease and cancer patients across England and speed up diagnosis.

Technology:

- Adopt new technologies to improve data capture and data use in clinical practice

Principle 12: Be innovative - worked examples from Spring 2021

Alström Syndrome Service, Bardet Biedl Syndrome Service, Wolfram Syndrome Service: Service co-ordinators send virtual clinic web links to patients with Top Tips sheets to ensure good virtual appointments.

Choriocarcinoma/Gestational Trophoblastic Disease: Specialist nurses have been triaging new referrals and have looked at extending their scope of practice.

Congenital Hyperinsulinism Service: During the pandemic, medical staff were redeployed to support Covid-19 wards and the clinical nurse specialist (CNS) team managed more of the patient workload within the scope of their clinical practise. The lead CNS triaged all referrals, using clear parameters.

Primary Ciliary Dyskinesia Management Service: Significant improvements were made to support patients at home during the pandemic with the provision of small items of home testing equipment. These measurement tools give comparable measurements to some of the tests that would have been done in face-to-face clinics. The service can now offer a hybrid model of care.

Retinoblastoma Service (Children): The adoption of new technologies for clinical practice and data capture, such as use of widefield digital imaging which has revolutionised the way information is captured.

> ‘The role of CNS changed during the pandemic and has been extended to include an increased role in helping to support the care and management of babies at home. Many patients who would previously be admitted for changes of mediations / treatment plans now remain at home and are supported with regular phone calls or virtual calls. This has benefited many patients and feedback has been very positive although has increased CNS workload…’, clinician Congenital Hyperinsulism Service for children.

Principle 13: Be consistently engaged

This principle asks acute trust teams to schedule regular virtual meetings with charities and stakeholder groups to agree audits, engage with patients to develop joint service improvement programmes or improve the effectiveness of virtual clinics.

Why is this a principle?

Many charities and stakeholder groups which support people with a rare condition already work with HSS teams to support patients; give feedback; forward patient enquiries and provide support on education and communication.

An example is the Headlines Craniofacial Support charity Headlines Craniofacial Support | Charity | United Kingdom which has published a Top 10 research questions to focus research on enabling a faster diagnosis and improved management of cases: https://www.headlines.org.uk/our-research-priorities

In the light of the new care model of virtual clinics for routine follow-ups, the learning from the HSS services is for there to be an ongoing programme of patient feedback and engagement with patient groups including on audit and research - to provide ideas on how care can be improved and to determine whether the needs of patients are being met.

Key resources:
https://www.gov.uk/government/publications/uk-rare-diseases-framework/the-uk-rare-diseases-framework

What should Trusts do?

Actions for acute trusts to consider:

- Consider how increased joint work with charity and stakeholder groups could improve the impact of virtual calls for patients and reduce the impact of barriers to access.
- Agree areas for joint audit and research which all parties can engage with.

Principle 13: Be consistently engaged - worked example from Spring 2021
Most HSS teams reported close collaboration with patients, families, carers and charities in pre-pandemic activities, and many became more frequent during the pandemic including any changes to self-isolating guidance; how to stay well; teaching sessions on how to use virtual clinic appointments and how to use the home testing equipment and in family days.

Principle 14: Be allied

This principle asks acute trust teams to engage with key strategic partners to support the adoption of new digital initiatives, seek out new funding streams and identify new care models. It also asks how the wider context for acute trust services can improve the availability and use of digital software and products in clinical care.

Why is this a principle?

It is important to remain on top of new developments in the field and remain engaged with key stakeholders. In rare disease services, this includes following changes in genomics, pursuing research opportunities, gaining wider knowledge to improve clinical practice enabled by big data and AI. The NHS's understanding of how treatments will benefit individuals based on new information or new ways of analysing data will be impacted by these developments.

What should Trusts do?

Actions for acute trusts to consider:

- Review how 'big data', AI, machine learning and innovative data use and storage opportunities could improve timely and informed decision making and ultimately the quality of outcomes for patients.
    - This could include
        - pilots for patient data held centrally in the cloud and permissions given to identified users to access it for use in face-to-face and virtual clinics. Users could include users in primary care including school nurses, secondary and specialist care providers.
- Review how national and international changes to clinical practice will benefit models and outcomes for patients.

Principle 14: Be allied - worked examples from Spring 2021

Primary Ciliary Dyskinesia Management Service (Children), Primary Ciliary Dyskinesia Diagnostic service (All Ages): The UK Research Strategy will have huge implications for the use of genomics in the UK given that it is wide-reaching, ambitious, and long-term in its outlook:

- The team use machine learning through an NIHR funded research programme to improve aspects of the diagnosis for PCD;
- The AI programme is already showing that it is very accurate, fast and in some specific cases better than clinical experts at detecting the more subtle electron microscopy (EM) defects that can be tricky to visualise by the human eye. It’s exciting and will hopefully improve speed, accuracy and reduce costs of EM diagnosis. Newly commissioned Genomic labs have enabled faster diagnosis for the PCD service;
- There are ongoing programmes using RNA sequencing for gene discovery and a PCD gene database is planned. Patients are being genotyped with a diagnosis and the service has secured a genetic diagnosis in 76% of the cohort.

“The UK Research Strategy will undoubtedly have huge implications for the future of genomics in the UK given it is wide-reaching, ambitious, and long-term in its outlook. We have moved into machine learning through an NIHR funded research programme to try and improve aspects of the diagnosis for PCD…” clinician, Primary Ciliary Dyskinesia Management Service

Conclusion

This guidance document is for acute teams who are interested in creating or improving virtual calls for the follow up of stable patients.

The HSS clinical teams and staff from charities who contributed to the creation of this document have shared their learning in good faith.

Abbreviations/Glossary

Abbreviation	Item	Description
	Alert Card	Specialised services and other services across the NHS provide patients who have a long term or other health condition with a paper credit card or A4 sized sheet or a link to an online platform with their medical and current treatments to carry with them to give to any hospital practitioner in the event of a medical emergency.
AI	Artificial Intelligence	The theory and development of computer systems able to perform tasks normally requiring human intelligence, such as visual perception, speech recognition, decision-making, and translation between languages. artificial intelligence definition - Search (bing.com)
	Care co-ordination, care co-ordinator(s)	Care co-ordinators help to co-ordinate and navigate care across the health and care system, helping people make the right connections, with the right teams at the right time. They can support people to become more active in their own health and care and are skilled in assessing people's changing needs. Care co-ordinators are effective in bringing together multidisciplinary teams to support people's complex health and care needs.They can be an effective intervention in supporting people to stay well particularly those with long term conditions, multiple long-term conditions, and people living with or at risk of frailty. NHS England » Care co-ordinators
CGMs	Continuous Glucose Monitoring Systems	A continuous glucose monitor (CGM) is a device used for monitoring blood glucose on a continual basis by insulin-requiring people with diabetes, e.g. people with type I, type II diabetes or other types of diabetes (e.g. gestational diabetes). These have a sensor which transmits to a screen which displays the data to the patient. Continuous glucose monitor - Wikipedia
CNS	Clinical Nurse Specialist	A Clinical Nurse Specialist (CNS) provides direct care to PATIENTS in one of a range of specialties, such as paediatrics, emergency care and oncology. Clinical Nurse Specialist (datadictionary.nhs.uk)
	Clinical Registries	NHS Digital runs clinical audits and registries for the health and care system in England. We help partners like the Department of Health and the Healthcare Quality Improvement Partnership compare the performance of health and care services against standards and national trends so that they can improve patient outcomes Clinical audits and registries - NHS Digital

Abbreviation	Item	Description
DHSC	Department of Health and Social Care	The Department of Health and Social Care on GOV.UK. supports ministers in leading the nation's health and social care to help people live more independent, healthier lives for longer. Department of Health and Social Care - GOV.UK (www.gov.uk)
	Digital Ambassadors	There are a number of programmes to support staff and those who engage with NHS users to become more expert at offering or using virtual care and other forms of online care offers to patients. Digital Health Ambassadors - Transformation Partners in Health and Care ; Become an NHS App ambassador - NHS Digital
	Digital Fellowships (TOPOL programme)	Health Education England offers Topol Programme Digital Fellowships to support staff to improve their understanding of virtual care, see https://www.hee.nhs.uk/our-work/topol-review
EM	Electron microscopy	A technique which uses next-generation sequencing (NGS) to reveal the presence and quantity of RNA in a biological sample at a given moment, analysing the continuously changing cellular transcriptome
	Digital Inclusion Guide	The NHS Digital inclusion Guide https://www.goodthingsfoundation.org/sites/default/files/personas_no_support.pdf) has been produced for NHS staff to support patients accessing digital clinics and care.
EPIC	EPIC is the name of an electronic patient record system used by hospitals	A brand of NHS patient electronic notes systems used by hospitals. Other software brands are available.
	Genomic Medicine Alliances	There are seven NHS GMS Alliances that oversee and coordinate the embedding of genomics into mainstream clinical care and the link with personalised medicine. NHS England » NHS Genomic Medicine Service Alliances to help embed genomics into patient care pathways
	Hybrid [model of care]: a mix of virtual and face to face appointments.	Term usually used to describe where there is a mix of both face-to-face clinic appointments and telephone or virtual calls.
	Home testing and monitoring	Where patients have testing and monitoring equipment at home to test themselves and usually send results to clinicians such as their GP or a local or specialist hospital to assist in the monitoring of their disease condition.
	Highly Specialised Service (HSS)	Highly specialised services are provided to a smaller number of patients compared to specialised services; usually no more than 500 patients per year. For this reason they are typically best delivered

		nationally through a very small number of centres of excellence. NHS commissioning » Highly specialised services (england.nhs.uk)
	Highly Specialised Service provider/unit	A hospital organisation which has been contracted by NHS England to provide a HSS service.
	HSS Virtual Care guidance	This document is guidance to acute trust providers on offering virtual clinics. It is based on the experience of highly specialised services which support patients with rare and complex and multi-system disorders.
	Integrated Care Boards (ICBs)	Integrated care systems (ICSs) are partnerships of organisations that were formed on 1 July 2022 to plan and deliver joined up health and care services and improve the lives of people who live and work in their area. ICBs are statutory NHS organisations responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in the ICS area. The establishment of ICBs resulted in clinical commissioning groups (CCGs) being closed down. NHS England » Integrated care boards in England
	Machine Learning	An application of artificial intelligence (AI) that provides systems the ability to automatically learn and improve from experience without being explicitly programmed. Machine learning - Wikipedia
MDT	Multi-disciplinary team	Multidisciplinary teams (MDTs) are teams of professionals who work together in the specialist service to manage a patient's care. Document template (england.nhs.uk)
	NHS Long Term Plan	In 2019 the NHS in England published The Long Term Plan document to enable it to be fit for the future and is based on the experiences of patients and staff. https://www.longtermplan.nhs.uk/
	Safeguarding	NHS England is dedicated in ensuring that the principles and duties of safeguarding children, young people, and adults at risk are holistically, consistently and conscientiously applied with the wellbeing of all, at the heart of what we do. NHS England » About NHS England Safeguarding
	Shared care agreements	Clinical care pathway document which sets out the future care needs of a patient for a specific health condition and enables the care and treatment you receive condition to be shared between the hospital and your GP. Details which teams are providing elements of the care needed.
	Transition	Name of the process when a paediatric patient in a children's service is clinically transferred to an adult service, this requires careful planning and preparation involving the child and their parents/carers.
	Virtual call/clinic/ appointment	Video or online clinical appointment where the patient dials into this using their mobile phone or an online platform link provided by the healthcare provider.

Appendices

Appendix 1: HSS Virtual Care guidance - Gap analysis and implementation planning template
Appendix 2: Contributors to the engagement process for the development of the HSS Virtual Care Toolkit
Appendix 3: COVID-19 nationally funded Home Testing Equipment supplied to HSS
Appendix 4: The contribution of the use of the HSS Virtual Care Toolkit to improvements in the management of rare disease

Appendix 1: HSS Virtual Care guidance - Gap analysis and implementation planning template

Acute trust teams can use this template when creating or improving the safety and effectiveness of existing virtual clinics.

Changing a service model from predominantly face to face to a hybrid model with virtual clinic appointments may involve a series of incremental service improvement changes and larger step changes.

	1	2	3	4
	Service inserts description of current digital care offer	**Service's aim for its future care offer**	**GAP between current position and future aim**	**Actions to close gap (then review cross-cutting themes)**
1 Be accessible **Action**: Consider 'digital poverty' that is the physical or geographical access barriers for people who are accessing some elements of a service virtually. (worked example)	Service covers three counties and includes an area of deprivation with low levels of access to smartphones or laptops in some cases and poor internet connectivity. Part of it is rural with infrequent transport links. There are some safeguarding cases spread across the area and some patients with	To be able to offer routine use of virtual follow up appointments to patients and their families for this condition, alternating with face-to-face appointments or with nurse led catch up calls in between clinic appointments.	Lack of smartphones or laptops in some families. Transport can be infrequent in some parts of the county. Patient needs to be reviewed regularly to ensure medicines compliance. People with complex care presentations	Area 1: Look at charitable funds and national schemes for access to laptops for specific families; work with charities for this condition on care co-ordinating appointment times and advice on how to access virtual clinics. Action: 1 Action: 2 Area 2: Can some of the monitoring be done more locally and the results fed through to this service.

	very complex care needs.		need additional monitoring	Action 1: Action 2: Area 3: Consider for each patient the appropriate frequency of face to face and virtual calls. Can they alternate? Action 1: Action 2:
2 Be flexible **Action:** Consider options for local testing; diagnostics, monitoring and medicines at home or in primary care; in new diagnostic hubs; and local hospital units as well as in national HSS units.				
3 Be informed – **Action:** Consider widening the membership of the MDT to include members of relevant regional specialty clinics and local clinicians who are managing a patient’s care.				
4 Be present **Action:** Ensure that patients and families/cares follow the virtual clinic planning guidance provided by the clinical team including: ‘Be ready, Be timely, Be present; Be charged up and ready to go; Think small’.				
5 Be safe and governed				

Action: Consider how to improve safeguarding in virtual clinics, safely manage complex cases and to bolster clinical governance processes.				
6 Be a listening team **Action:** Give the patient the opportunity to speak and raise any questions/issues, as well as listening to parents or carers who may also be in the room and who may want to lead the conversation.				
7 Be equitable **Action:** Promote health equality, not worsen health inequalities when offering virtual clinic appointments.				
8 Be compassionate **Action**: Consider the options/ best ways to break difficult news when there are difficulties for patients to travel to clinic.				
9 Be co-ordinated and share patient management and care plans **Action:** Clarify who is co-ordinating each element of the patient's care plan through written shared care agreements and communicate these				

to key clinical staff in the patient's network of care.				
10 Be prepared: Action: Add emergency management escalation plans information to existing hand-held Patient-held Alert Cards.				
11 Be collaborative. **Action:** Consider ways to collaborate more with leads across NHS pathways, social care, charity and education teams.				
12 Be innovative Action: Consider making changes to people, process and technology functions within the care pathway to increase the successful implementation of these as part of virtual clinics. This includes planning to adopt new technological systems; digital tools; increased use of artificial intelligence (AI), big data and machine learning to improve the use of data in clinical practice and to maximise use from existing systems such as clinical registries.				

13 Be consistently engaged **Action**: Schedule regular virtual meetings with charities and stakeholder groups to agree audits, engage with patients to develop joint service improvement programmes or improve the effectiveness of virtual clinics.				
14 Be allied **Action**: Engage with key strategic partners and programmes to support adoption of new virtual and digital initiatives, funding streams and identify new care models.				

Appendix 2: Contributors to the engagement process for the development of the HSS Virtual Care guidance

Grateful thanks are extended to the following clinical service teams, charity staff and the patients, families and carers of these rare disease services for their participation in informing the HSS commissioning team on establishing the issues, benefits and disbenefits of virtual calls.

A series of engagement calls took place over the two years of the COVID-19 pandemic to date as follows:

- March, April, May 2020 COVID-19 video engagement events held with a MDT staff from HSS services, charities and patients of all ages and their families/carers to determine experience of patients/families/carers and clinical teams of changes to providing urgent, emergency and routine (new and follow up) care during the pandemic – issues, concerns;
- On 25th February, 11th March and 29th April 2021, engagement events with MDT clinicians and charity groups to discuss early drafts of the HSS Digital Care Strategy for 2021-2025 and contribute to findings to the NHSE wider engagement for the Rare Disease Framework England Action Plan. In all, 50 clinicians and charity team attendees joined the calls and/or sent email comments to be incorporated into later versions of the paper;
- RCPCH CHI Special Interest Group 30 03 2021;
- A review of the use of the RDE bloods service on 15th September 2021 attended by the clinical services who are in receipt of the service.

HSS	**Name and Trust/Charitable Organisation**
Ataxia telangiectasia service (children)	Kay Atkins, Anne Murray - The AT Society; Sandra Hufton, Dr Mohnish Suri, Nottingham University Hospitals NHS Trust.
Alström syndrome	Kerry Leeson-Beavers, Alström Syndrome UK; Professor Tim Barrett, Birmingham Women's and Children's NHS Foundation Trust; Dr Tarekegn Geberhiwot, University Hospitals Birmingham NHS Foundation Trust.
Bardet Biedl syndrome service	Professor Tim Barrett, Birmingham Women's and Children's NHS Foundation Trust; Dr Shehla Mohammed, Guy's and St Thomas' NHS Foundation Trust;

	Professor Phil Beales, Great Ormond Street Hospital for Children NHS Foundation Trust; Kath Sparks, Great Ormond Street Hospital for Children NHS Foundation Trust and Guy's and St Thomas' NHS Foundation Trust; Angela Scudder, Tonia Hymers, BBS UK.
Complex neurofibromatosis Type 1	Professor Rosalie Ferner, Guy's and St Thomas' NHS Foundation Trust; Dr Vassallo Grace, Manchester University NHS Foundation Trust.
Complex congenital osteogenesis imperfecta	Dr Catherine Devile, Great Ormond Street Hospital for Children NHS Foundation Trust.
Congenital hyperinsulinism service	Dr Maria Salomon-Estebanez, Dr Indi Banerjee, Elaine O'Shea, Manchester University NHS Foundation Trust; Dr Antonia Dastamani and Clare Gilbert, Great Ormond Street Hospital for Children NHS Foundation Trust.
Craniofacial Services	Karen Wilkinson-Bell, Headlines Craniofacial Support Group; Mr Chris Parks Alder Hey Children's NHS Foundation Trust.
Gestational Trophoblastic Disease/ Choriocarcinoma (All Ages)	Xianne Aguiar, Imperial College Healthcare NHS Trust.
Multiple Sclerosis Management Service for Children	Liam Barford, Cambridge University Hospitals NHS Foundation Trust Dr Cheryl Hemingway, Great Ormond Street Hospital for Children NHS Foundation Trust; Rachel Hubball, Birmingham Women's and Children's Hospital NHS Foundation Trust; Ruth MacLeod, MS Society; Dr Siobhan West, Manchester University NHS Foundation Trust; Claire Winchester, MS Trust.
NF2-Schwannnomatosis (All ages)	Professor Gareth Evans, Manchester University NHS Foundation Trust; Dr Juliette Buttimore, Cambridge University Hospitals NHS Foundation Trust.
NHS England	Fiona Marley, Dr Ayesha Ali, Asma Hasan, Nicola Symes, Sue Trew, Sarah Watson, Joan Ward, Andy Stewart, Bernie Stocks
Open pre-natal surgery to treat fetuses with open spina bifida	Emma Bredaki, University College London Hospitals NHS Foundation Trust and Great Ormond Street Hospital for Children NHS Foundation Trust and University Hospitals Leuven, Belgium; Andy Wynd, Spina Bifida Hydrocephalus Scotland; Gill Yaz, Shine.

Primary Ciliary Dyskinesia Diagnostic Service (All ages)	Dr Siobhan Carr Royal Brompton Hospital, part of Guy's and St Thomas' NHS Foundation Trust; Professor Jane Lucas, University Hospital Southampton NHS Foundation Trust.
Primary Ciliary Dyskinesia Management Service (Children)	Professor Claire Hogg, Royal Brompton Hospital, part of Guy's and St Thomas's NHS Foundation Trust; Dr Manjith Narayanan, University Hospitals of Leicester NHS Trust; Dr Evie Robson, Leeds Teaching Hospitals NHS Trust; Dr Woolf Walker, University Hospital Southampton NHS Foundation Trust.
Specialist Liver Disease Service (Children)	Harpreet Brrang, Children's Liver Disease Foundation.
Retinoblastoma Service (Children)	Mr Ashwin Reddy, Barts Health NHS Trust; Mr Manoj Parulekar and Professor Bruce Morland, Birmingham Women's and Children's NHS Foundation Trust.
Wolfram Syndrome Service (All Ages)	Tracy Lynch Wolfram Syndrome UK; Dr Renuka Dias and Professor Tim Barrett, Birmingham Women's and Children's NHS Foundation Trust.
Vein of Galen Malformation Service (Children)	Dr Sanjay Bhate, Great Ormond Street Hospital for Children NHS Foundation Trust

Appendix 3: COVID-19 national pilot funding for Home Testing Equipment awarded to HSS in April 2020 when patients couldn’t attend hospital for routine follow ups.

- Blood pressure monitors
- Continuous glucose monitoring machines
- Distraction Therapy kit
- Headspace app for managing anxiety
- Height scales
- Home dried blood spot testing
- Home blood capillary testing
- Home delivery of chemotherapy medicinal product – this did not proceed but is still planned
- Online app for psychology/neuropsychology assessment and management, followed up by 1:1 training in a smaller number of patients
- Peak flow meters
- Sim free mobile phone for app for data capture of blood glucose and diet
- Spirometer (with/without app)
- Tactile measuring tapes
- Talking bathroom scales
- Urinary Tract Infection home testing kits

Appendix 4: The contribution of the use of the HSS Virtual Care guidance to improvements in management of rare disease

The use of this HSS Virtual care guidance by acute hospitals will support the delivery of two key strategies:

- **The NHS Long Term Plan**

The use of this HSS Virtual care guidance by acute hospitals in conjunction with their commissioners including Integrated Care Boards (ICBs), will support the delivery of priority 1 of NHSE Long Term Plan (LTP) to drive NHS digital transformation. This includes the following LTP priorities in particular:

- Create straightforward digital access to NHS services and help patients and their carers manage their health.
- Use decision support and artificial intelligence (AI) to help clinicians in applying best practice, eliminate unwarranted variation across the whole pathway of care, and support patients in managing their health and condition.
- Link clinical, genomic and other data to support the development of new treatments to improve the NHS, making data captured for care available for clinical research, and publish, as open data, aggregate metrics about NHS performance and services

- **The Department of Health and Social Care (DHSC) Rare Disease Framework Jan 2021**

The DHSC undertook a programme of engagement to understand the main challenges for those living and working with rare diseases across the UK and how these could be addressed to set the priorities for the next 5 years. The UK Rare Diseases Framework has priorities and underpinning themes as follows:

Priorities: 1. Ensuring patients get the right diagnosis faster; 2. Increasing awareness of rare diseases among healthcare professionals; 3. Better co-ordination of care; 4. Improving access to specialist care, treatments and drugs

Underpinning themes: 1. Patient voice; 2. National and international collaboration; 3. Pioneering research; 4. Digital, data and technology 5. Wider policy alignment

The use of the HSS Virtual Care guidance by HSS and acute hospital teams will support the delivery of:

- Priority 2: Increasing awareness of rare diseases among healthcare professionals by engaging with local teams and the enhanced MDT where appropriate,
- Priority 3: Better co-ordination of care by contributing to an understanding of each patient or group of patients with similar needs and establishing ways in which they can feed back data and other information on their status to clinical teams via email or telephone or via online systems. This may be aided by using low-cost, low-tech home monitoring equipment.
- The fourth underpinning theme: Digital, data and technology – using more opportunities to connect with patients and their other key clinicians via digital means as well as face to face.

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