Cover note for CONCORD flow chart demonstrating how taxonomy options can be used to develop models of care coordination

How has this flow chart been developed?

This flow chart has been developed from the qualitative CONCORD study which aimed to develop a taxonomy of different ways of coordinating care for rare conditions.

These findings are based on 30 interviews with healthcare providers, commissioners and charity representatives, and four focus groups with patients and carers with experience of rare, ultra-rare or undiagnosed conditions. The decisions within this flow chart are based on findings of different ways of coordinating care and stakeholder's preferences, benefits/challenges of different models, factors influencing coordination and barriers/facilitators (as presented in the CONCORD workshops).

What is the CONCORD flow chart?

- The CONCORD flow chart is a visual representation of the findings from the CONCORD taxonomy study, and has been used by the CONCORD researchers to visualise how different ways of coordinating care may be used in certain situations. The flow chart could also potentially be used by commissioners/clinicians when thinking about how to coordinate care for people living with rare conditions.

How has the CONCORD flow chart been used so far?

- This flow chart has been used to develop potential hypothetical models of care coordination which take into account different situations. (Please see handout: 'Hypothetical models of care coordination_06012021').
- Whilst this flow chart has been used to develop hypothetical models, it has not yet been tested as such.

How to use the CONCORD flow chart

- There is flexibility needed in interpreting the CONCORD flow chart.
- When using the flow chart, it may be helpful to start in the top left hand corner, with the question 'Can the patient/carer coordinate their own care?'
- Within each decision box (the boxes that are fully shaded), there are multiple options that may be suitable (e.g. the type of technology used, type of mode, or who coordinates care). Additionally, in some cases 'sometimes' may be appropriate, or individuals' needs and situations may change.
- This flow chart is therefore a guide and may not account for all possible options. The flow chart may instead support discussion and thinking around which models may suit different situations.
- Further work would be necessary to ensure that this would be fit for purpose if it were to be used as a decisional tool.

Where to start?

- The different colour boxes represent the six domains of the CONCORD taxonomy
  - Orange = ways of organising care
  - Green = ways of organising teams
  - Blue = responsibilities
  - Yellow = access to records and frequency of appointments
  - Purple = mode
- The domains can be thought about it any order. However, as all six domains have been found to be important in coordinating care, it is important that each domain is considered when thinking about your options.

CONCORD STUDY
Coordinated Care of Rare Diseases

CONCORD Flow Chart demonstrating how taxonomy options can be used to develop models of care coordination

PLEASE START HERE

Can the patient/carer coordinate their own care?
- Yes
- No

Does the patient/carer want to coordinate their own care?
- Yes

Does the patient/carer have additional needs or condition complexities that require clinical coordination?
- Yes

Level of care coordination needed*

Patient/carer coordinates with access to minimal support from named person

Patient/carer has support from a care coordinator (examples include a nurse, charity support workers, AHPs, transition coordinator)

Patient/carer has support from a clinical coordinator (examples include a doctor or GP)

* Who coordinates care as depending on provider and local healthcare environment resources and may include direct involvement from charities

Does the patient require regular care appointments or coordination (e.g. due to guidelines, condition or age etc)?
- No
- Yes

Is the condition stable?
- No
- Yes

Does the family have additional needs that require more frequent appointments?
- Yes

On demand patient led appointments and/or coordination

Regular appointments → + On demand appointments where necessary /possible

Are digital and/or telephone modes available?
- Yes
- No

Does the patient need to be seen face-to-face (e.g. because of condition, treatment and/or individual needs etc.)?
- Yes, all of the time
- Yes, sometimes
- No

Face-to-face appointments and/or coordination only

A combination of face-to-face, digital and telephone appointments for care delivery and/or coordination**

A combination of digital and telephone appointments for care delivery and/or coordination**

** Balance of different modes as determined by needs

Does the patient need to see a specialist?
- Yes
- No

Does the patient live near the service (or if regional – one of the services)
- Yes
- No

Would the patient benefit from attending a specialist service? (e.g. due to age or condition)
- No

Is there at least one funded specialist service?
- Yes
- No

Care at specialist (national or regional) service

Administrative staff based at specialist centre and acting as point of contact for patients and healthcare professionals

Specialist provider with expertise acting as clinical lead for the patient

Specialist service to coordinate appointments (joint coordinator, transition (transition coordinator) and arrange provision of necessary level of coordination*

Can the patient or family travel?
- No
- Yes

Does the patient want to travel?
- Yes

Outreach care provided locally or remotely, in conjunction with specialist centre (hub and spokes model)

Care split between specialist service and local care (e.g. hub and spokes, network)

Local care (e.g. for conditions that are not discrete)

Local provider or charity acting as a point of contact

Local providers (i.e. GP or community paediatrician act as clinical lead for the patient

Local provider to coordinate appointments and provision of necessary level of coordination*

* Who coordinates care as depending on provider and local healthcare environment resources

PLEASE NOTE
- Please refer to the CONCORD flow chart cover note for details on what this flow chart is and how it has been used
- Note – the 'care' described in this flow chart refers to both health and social care, throughout a person's life.

Does the condition or situation suit team working? (e.g. is the condition discreet, suitably complex and requires specialists, or is it a key point in the pathway e.g. transition?)
- No

Lack of collaboration → individual appointments

Can all professionals* meet to discuss care?
- No

Can all professionals* work together in one clinic?

* Professionals refers to all those involved in health and social care

Do the patients and carers need support to prepare them for the next stage of care? (e.g. around transition periods)

Orientation visits/transition events/advice and support

Is it appropriate for patients to join the meeting?
- Yes
- No

Is a condition-specific clinic available?
- No

Can some professionals* work together in one clinic?
- Yes

MDT meetings with patient/parent

MDT meetings without patient/parent

Condition specific clinic / one stop shop

Joint clinics

Is there an appropriate infrastructure for sharing of information digitally?
- Yes
- No

Does the infrastructure allow for national sharing?
- Yes
- No

Can information be shared with patients?
- No
- Yes

Do providers share information between them and with patients?
- No
- Yes

Lack of information sharing

Digital methods (e.g. national access to records, national databases and national portals)

Digital methods (local access to records, databases and portals)

Digital methods (e.g. online portals, letters, applications etc)

Written methods of information sharing (e.g. letters, records, care plans, responsibility agreements and guidelines)

Is the patient happy for their records/information to be shared and accessible to healthcare professionals?
- No
- Yes

Patient has to be the owner of records and pass information to relevant healthcare professionals

Is the patient happy for their records to be shared with all healthcare professionals involved?
- No
- Yes

Patient has to be the owner of records and control who has access to records of or patient-held records

Full access for patients and healthcare professionals (e.g. through online records, online portal, patient held record)

Does the healthcare provider need access to the whole record?
- Yes
- No

Filtered records which are filtered according to need but accessible

*In some cases where charities are involved in provision of care it may be necessary for them to also have filtered access

Digital and telephone

Communication with patients

Communication between professionals

Digital, face to face and telephone communication