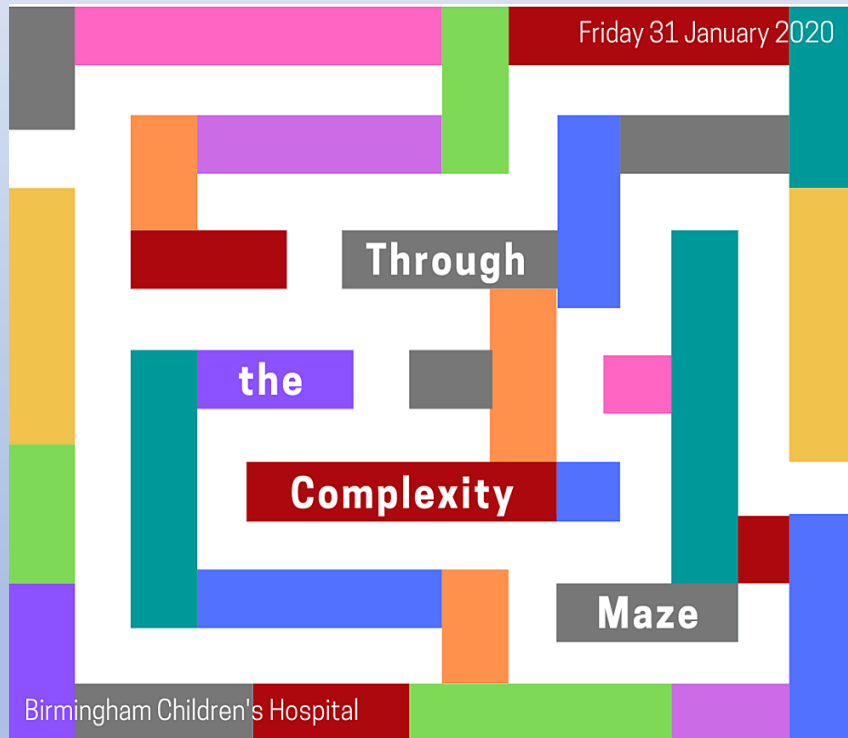


Welcome – Workshop

**Understanding the Evidence for New
and Existing Models of Care**



Professor Jane Coad

University of Nottingham & **Dr Lorna Fraser**

University of York (Co-leads)

Dr Ronny Cheung

Evelina London Children's Hospital

And Group Facilitators

Background - Workshop

- Queens Speech following the election confirmed new legislation including the **NHS Funding Bill and NHS Long Term Plan**
- Rising numbers of complex needs of children and young people (CYP)
- **Variety of ‘Models of Care’ across the UK** – NHS England acknowledge that there is not “one solution fits all”
- The *dance* of technology, access and awareness in current healthcare systems and organisations ...
- And there is need for sharing co-ordinated sharing in order to provide an uninterrupted, co-ordinated approach to healthcare across the care pathway and organisational boundaries
- Clinical leadership is key in the delivery of best models of care
- Fundamental to have CYP and family voice in all models of care

Background

Who we are in this workshop?

One of the groups within the CoLab committed to working together and sharing good practice, evidence and resources to improve understanding and co-ordination of models of care



Aim of the Workshop

- Define and agree what we mean by complex needs in CYP care
- Work together to share the key issues in terms of defining and delivering models of care

Our Starting Point!

DEFINITIONS

Importance of definitions

Definitions have the potential to provide clarity. At their best, **definitions** act like a compass

Working towards a **common understanding** to support targeted and integrated complex care interventions

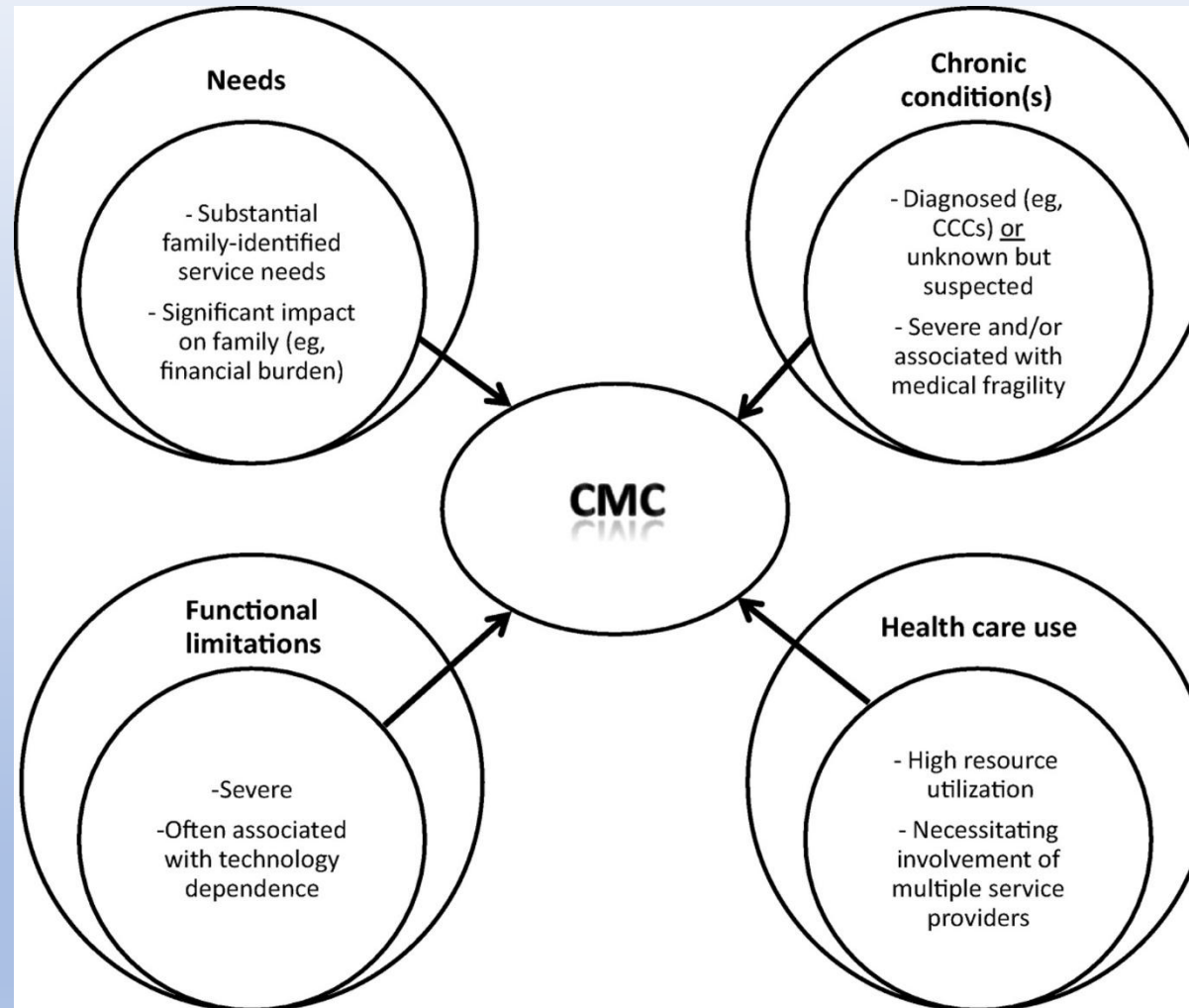
Research has found that within a structured clinical programme, a clear understanding from the start, may improve the health outcomes of **including** reducing the burden of caregiving, and mitigating costly and unnecessary healthcare expenditures



CURRENT DEFINITIONS

- Children with Medical Complexity (Cohen et al 2000)
- Complex Chronic Conditions (Feudtner et al 2000)
- Life-limiting Condition (Goldman 1999/Together for Short Lives)
- Medical Frailty (Siden et al)
- Disability Complexity Scale (Horridge et al 2016)
- Chronic Disease (Hardelid et al 2014)
- Long-Term Condition (Department of Health 2012)

Definitional framework for CMC among other definitions of chronic conditions of childhood.²⁵
In this framework, CMC are defined as children with characteristic patterns of needs, chronic conditions, functional limitations, and health care use.



Eyal Cohen et al. *Pediatrics* 2011;127:529-538

Chronic Complex Conditions (Feudtner et al)

“Any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center”

Life Limiting Conditions (Together for Short Lives 2016)

“Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die. Some conditions cause progressive deterioration, meaning that the child becomes increasingly dependent on parents and carers.

Life-threatening conditions are those for which curative treatment may be feasible but may fail“.

Disabilities Complexity Scale (Horridge et al)

The sum of overall needs was calculated for each child as well as the sum of health conditions (C), technology dependencies (T), family-reported issues (F), and need for round-the-clock care (R)

- Conditions includes underlying diagnoses and co-morbidities
- Technologies e.g. VP shunt, ventilation, tracheostomy, cochlear implant
- Family Reported issues e.g. child protection plan, family issues, school issues, housing issues, equipment issues
- The need for round the clock care

Chronic Disease (Hardelid et al 2014)

‘a chronic condition as any health problem likely to require follow-up for more than 1 year, where follow-up could be repeated hospital admission, specialist follow-up through outpatient department visits, medication or use of support services.’

Long Term Condition (Dept Health)

“Long-term conditions or chronic diseases are conditions for which there is currently no cure, and which are managed with drugs and other treatment”

Key Concepts in Current Definitions

- Diagnoses
- Functional Limitations
- Technologies
- Family needs
- Health care use

Complex Care for Kids Ontario Inclusion Criteria.

CCKO

Complex Care Kids Ontario

Standard Operational Definition for Children with Medical Complexity who are Medically Fragile and/or Technology Dependent

Under 18 years of age and meets at least one criterion from EACH of the following four conditions:

Technology Dependent
and/or users of High
Intensity Care

and

Fragility

and

Chronicity

and

Complexity

☐ Child is dependent on mechanical ventilators, and/or requires prolonged intravenous administration of nutritional substances or drugs and/or is expected to have prolonged dependence on other device-based support. For example: tracheostomy tube care/ artificial airway, suctioning, oxygen support or tube feeding.

☐ Child has prolonged dependence on medical devices to compensate for vital bodily functions, and requires daily/near daily nursing care, eg, cardiorespiratory monitors; renal dialysis due to kidney failure

☐ Child has any chronic condition that requires great level of care such as: Children who are completely physically dependent on others for activities of daily living (at an age when they would not otherwise be so dependent), Children who require constant medical or nursing supervision or monitoring, medication administration and/or the quantity of medication and therapy they receive.

☐ The child has severe and/or life-threatening condition
☐ Lack of availability and/or failure of equipment/technology or treatment places the child at immediate risk resulting in a negative health outcome
☐ Short-term changes in the child's health status (e.g., an intercurrent illness) put them at immediate serious health risk.

☐ As a consequence of the child's illness, the child remains at significant risk of unpredictable life-threatening deterioration, necessitating round-the-clock monitoring by a knowledgeable caregiver.

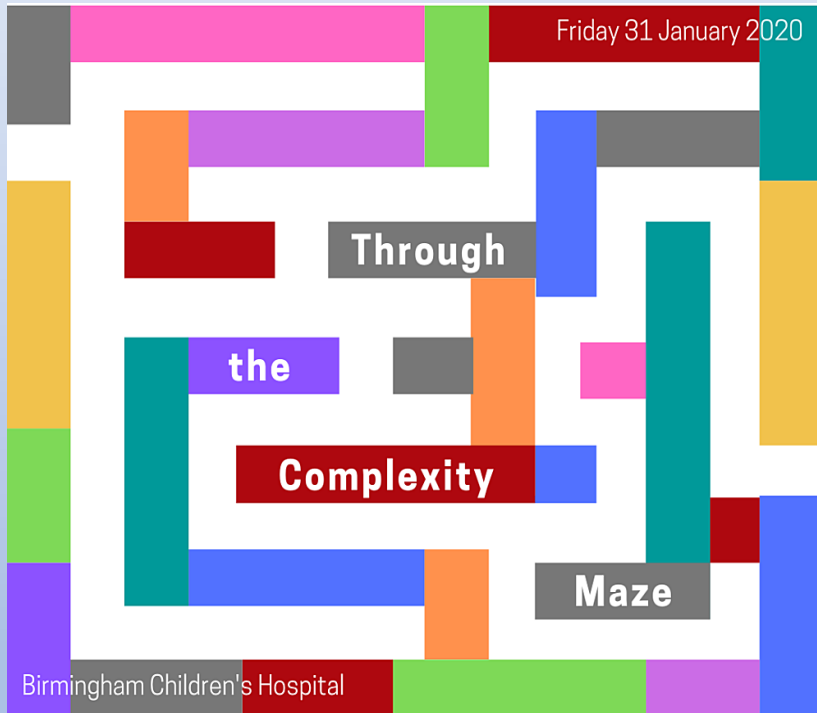
☐ Likely to experience exacerbation of chronic condition necessitating assessment by a healthcare provider in a timely manner

☐ The child's condition is expected to last at least six more months
☐ The child's life expectancy is <6 months

☐ Involvement of at least five healthcare practitioners/ teams and healthcare services are delivered in at least three of the following locations: Home, School / Nursing school, Hospital, Children's Treatment Centre, Community-based clinic (e.g. doctor's office), Other (at clinician's discretion)

☐ The family circumstances impede their ability to provide day-to-day care or decision-making for a child with medical complexity. For example, the primary caregiver and/or the primary income source are at risk of not being able to complete their day-to-day responsibilities

Over to you!



In groups we would like you to

1. Discuss definitions presented and add any of your own with reasoning
2. Agree on a consensus in your group about the definition and why
3. Facilitator will act as spokesperson in feedback
4. Overall consensus discussion

Finally

Thank you
Future Plans

Any questions?

Contacts: jane.coad@nottingham.ac.uk