

Innovative solutions for children's chronic pain



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Agenda

The issue of persistent pain in young people

Developing a new model

Involving young people in the research process

Evaluating the the new model



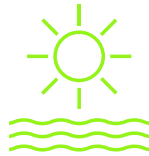
Definitions

- Chronic pain is pain that persists past normal tissue healing time or lasts/recurs for more than 3 to 6 months
- Chronic pain can be persistent (ongoing) and/or recurrent (episodic)

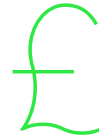
Chronic pain in children



Leading cause of morbidity affecting 20% to 35% of children worldwide



Significantly impacts quality of life



NHS spends £4 billion every year for adolescent pain alone



UK parents pay £900 out-of-pocket expenses a year



Work absences of 7 to 37 days costing on average £750 per family each year

Understanding Children's Experiences

- Qualitative evidence conveys experiences, perceptions, preferences
- No existing synthesis





Cochrane
Library

Cochrane Database of Systematic Reviews



A meta-ethnography of how children and young people with chronic non-cancer pain and their families experience and understand their condition, pain services, and treatments (Review)

France E, Uny I, Turley R, Thomson K, Noyes J, Jordan A, Forbat L, Caes L, Silveira Bianchim M

Review Questions

How do children and young people who have chronic pain and their families:

1. Think about chronic pain?
2. Live with chronic pain?
3. Think of how health and social care services treated their pain?
4. What do they want from services and treatments?



Findings



44 Included Publications



633 Participants – 325 children, 291 parents & 17 siblings



11 Countries – 4 low-to-mid-income and 7 high-income



15+ types of chronic pain/ conditions

What we found



The journey of living with chronic pain

- Family life and relationships
- Sense of normality
- Diagnosis
- Navigating services
- Impact of pain



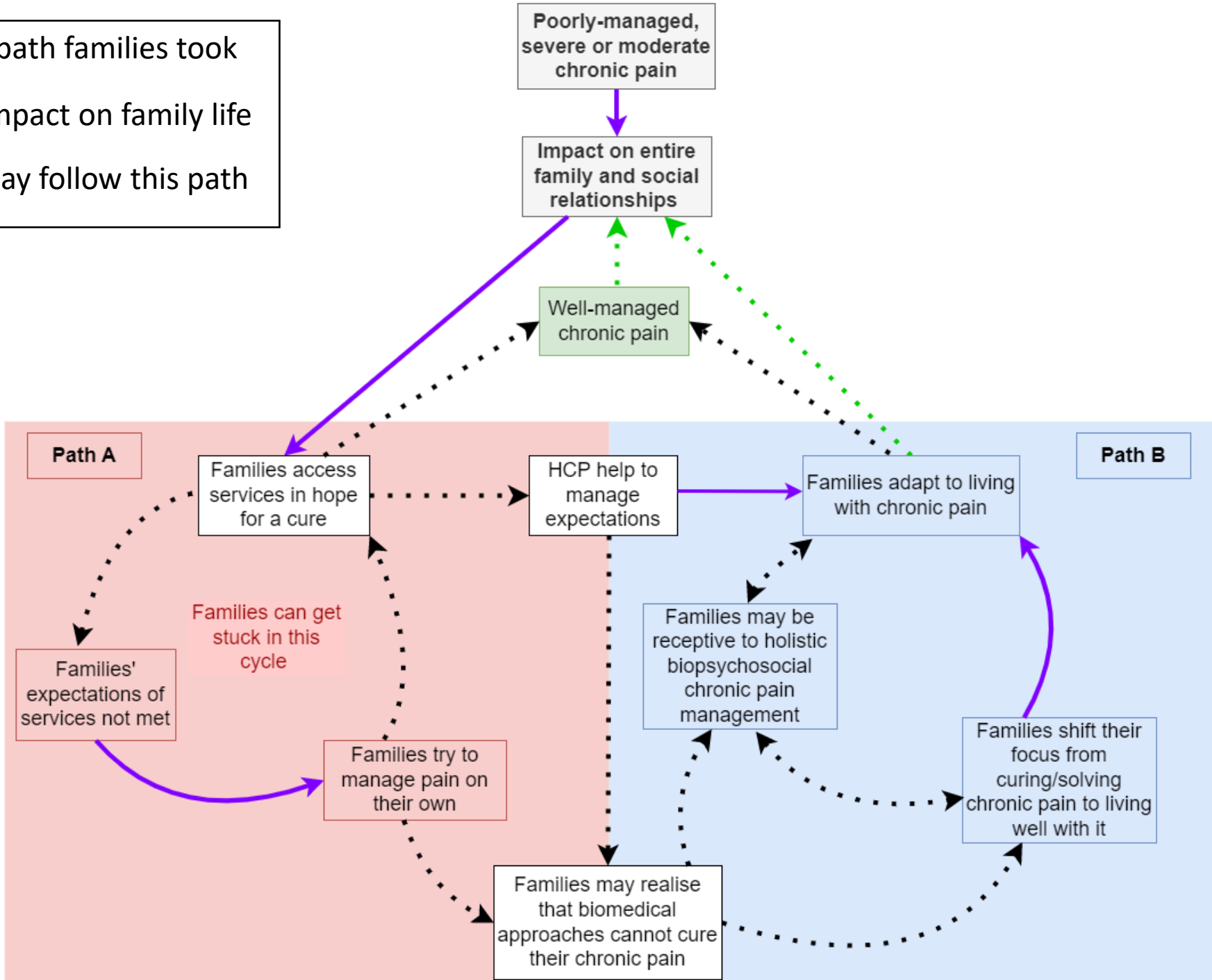
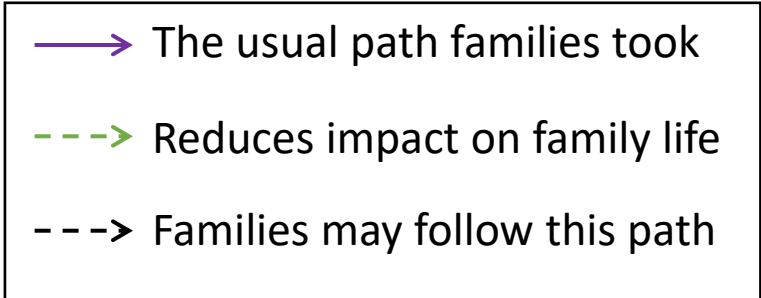
Dominance of biomedical perspective in how children & families conceptualise chronic pain & pain management



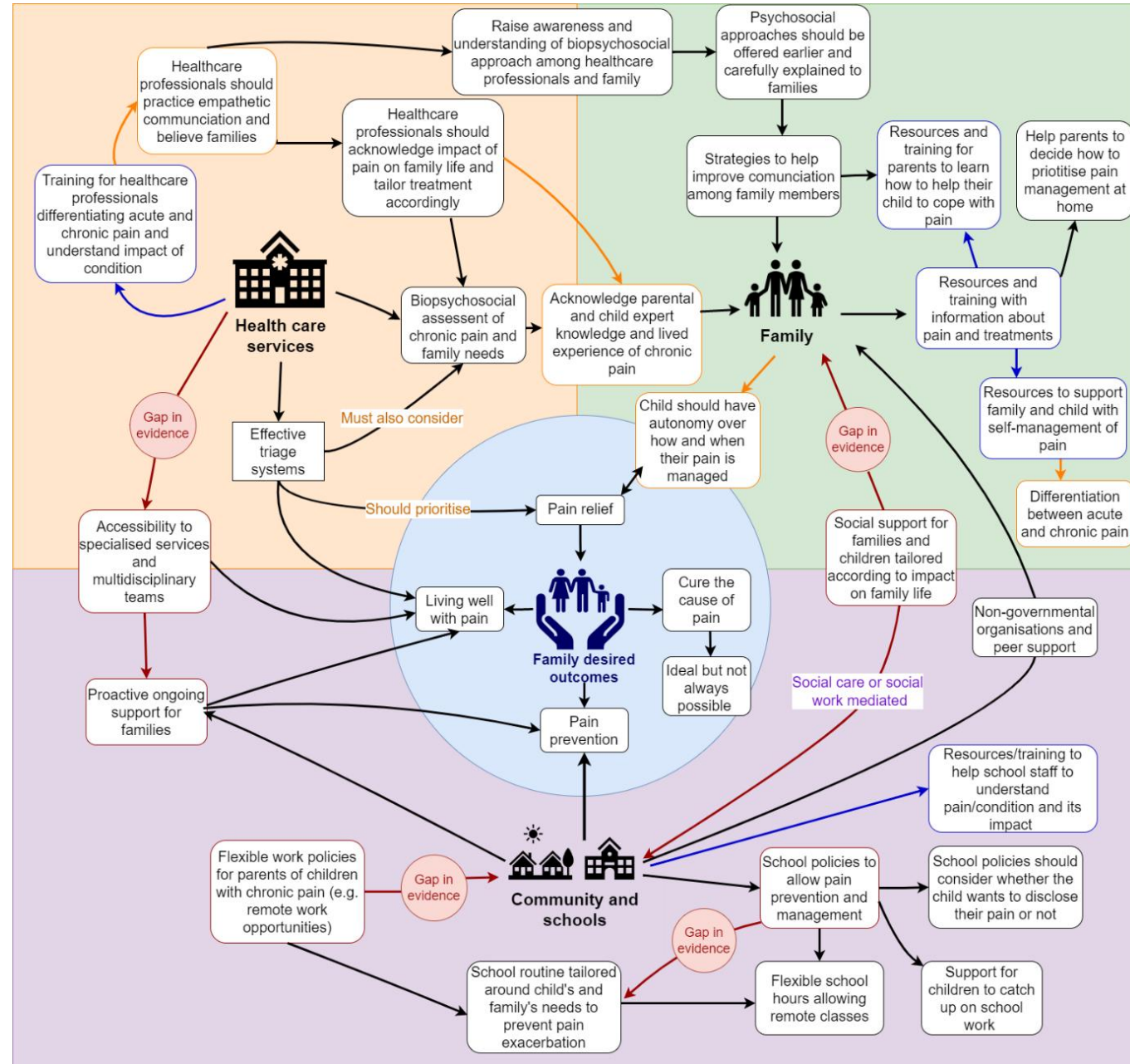
Parents fundamental to effective pain management

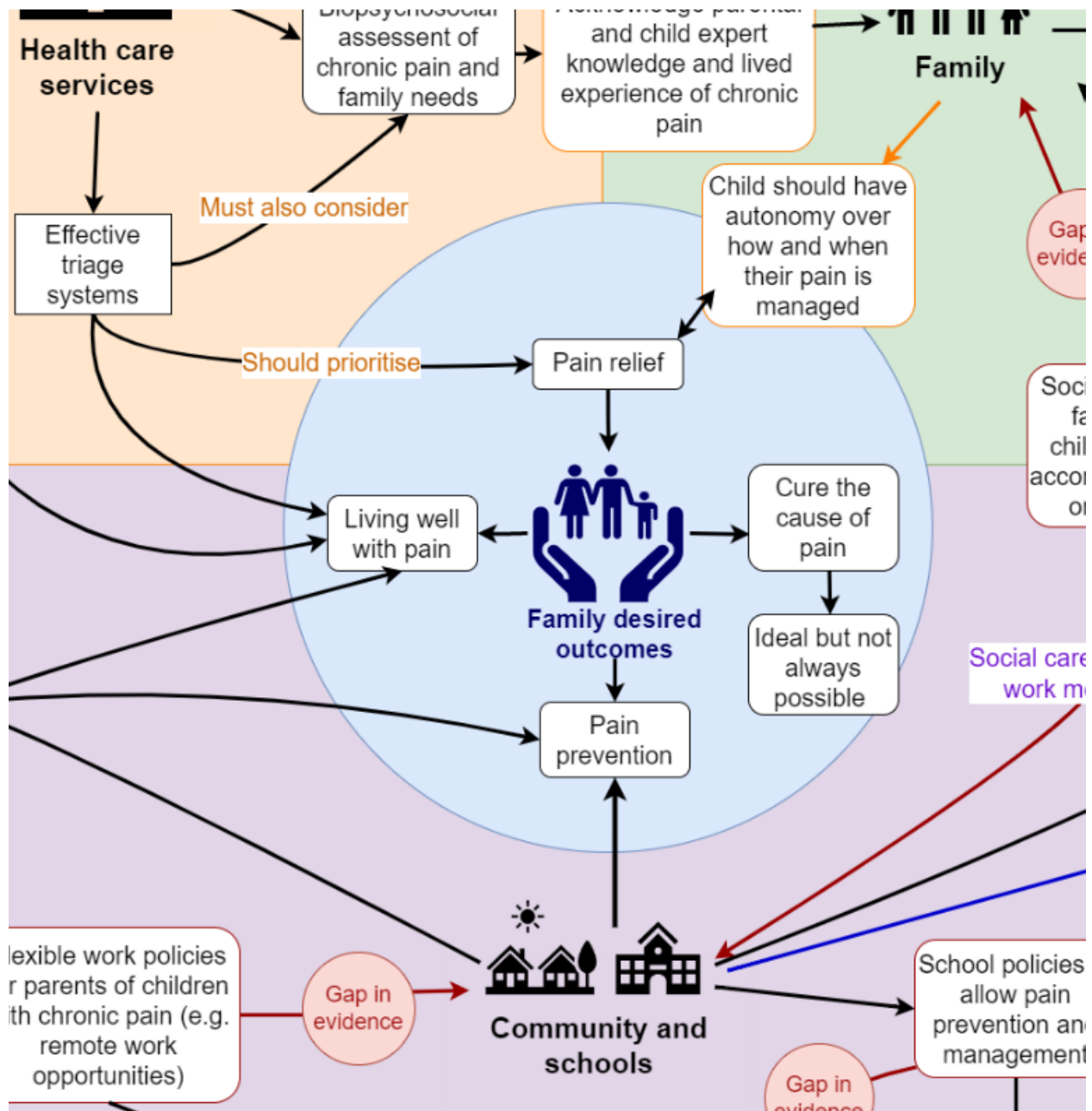
- Repetitive/painful
- Side effects
- Disruption
- Adherence
- Sharing responsibility





Family-centred theory of children & young people's chronic pain





Good pain management-key features

01

Biopsychosocial, family-centred pain management **integrated with support in the community**, tailored for children

02

Increased availability & accessibility of specialist **multidisciplinary pain management** for children with complex chronic pain problems

03

Improved education in children's chronic **pain assessment & management** for healthcare professionals

04

Development & **testing of a triage approach** to ensure the right care, at the right time, from the right service

05

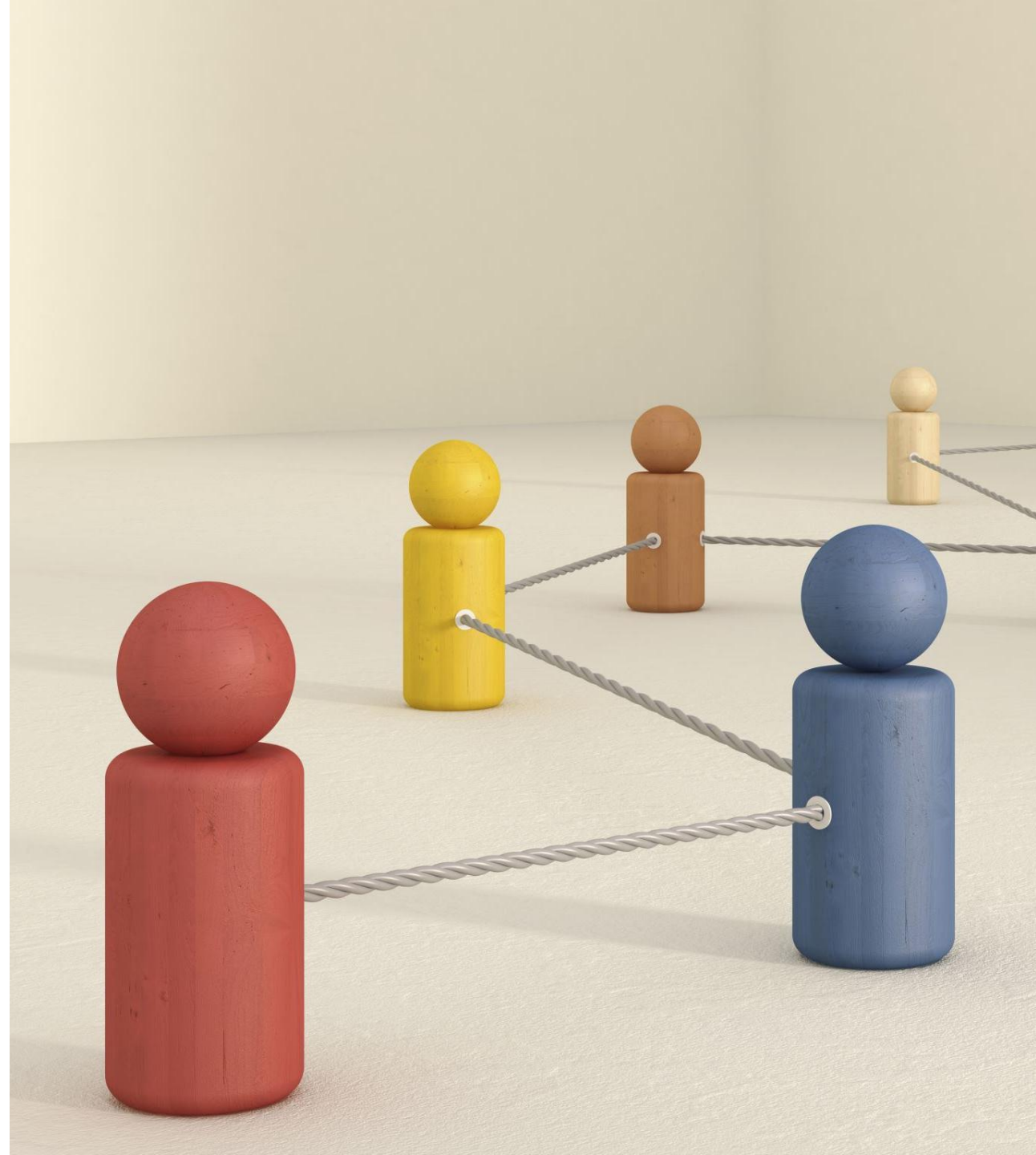
Clear **clinical care pathways**

An illustration of a roller coaster with three people in cars. The roller coaster is a wooden structure with a grey track, set against a dark grey background. The track is curving upwards. Three people are in the cars: a person in a yellow shirt in a red car, a person in a white shirt in a red car, and a person in a red shirt in an orange car. The roller coaster is framed by a purple border on the left, a green border on the right, and a blue border at the bottom.

The Chronic Pain Rollercoaster

Patient and public involvement (PPI)

- 12 children/young people (10 female, 1 male, 1 non-binary) aged 8–20 years with chronic pain.
- 8 parents all mothers of children with chronic pain.
- Demographics: Participants from England, Scotland, and Wales



	Meta-ethnography phases	How PPI was involved	Where PPI was involved
1	Selecting meta-ethnography	Lay language	Planning of proposal
2	Deciding what is relevant to the initial interest	Lay language and images	Search strategy and sampling
3	Reading the studies	Infographic	Grouping studies
4	Determining how the studies are related	Infographic	Grouping studies
5	Translating the studies into one another	Cartoons	Analysis and interpretation of findings
6	Synthesising translations	Cartoons	Analysis and interpretation of findings
7	Expressing the synthesis	Lay language and images	Producing outputs and delivering dissemination

PPI training

- Age-specific online surveys
- Training sessions on:
 - (i) How to use Zoom videoconferencing software,
 - (ii) Defining research,
 - (iii) Defining qualitative research, and
 - (iv) Defining meta-ethnography.



PPI Involvement in Data Analysis & Interpretation

- Cartoons and infographic

New Perspectives:

- PPI insights refined and expanded interpretations of findings
- Highlighted gaps and provided clarity to primary study findings



Mixed Feelings

Claire brings her daughter Julie home after a busy day. They are getting ready to go to sleep, but both have a lot on their minds.





CHAMPION PROJECT

We want to find out how young people who have chronic pain and their families:

- Think about chronic pain
- Think of how the NHS treated their pain
- Live with chronic pain
- What they want from the NHS



To answer these questions we looked for studies on chronic pain in young people



17 studies from all over the world



25 studies from the UK



42 studies in total on 10 different pain conditions



WE LOOKED AT



WE WILL LOOK AT



Blood Illnesses



Tummy Pain



Juvenile Arthritis



Joint Pain



Headache



Period Pain



Complex Regional Pain Syndrome



Brain illness



Skin Conditions



Mixed Illness

PPI Involvement in Dissemination



Co-production of video animation and podcast about chronic pain



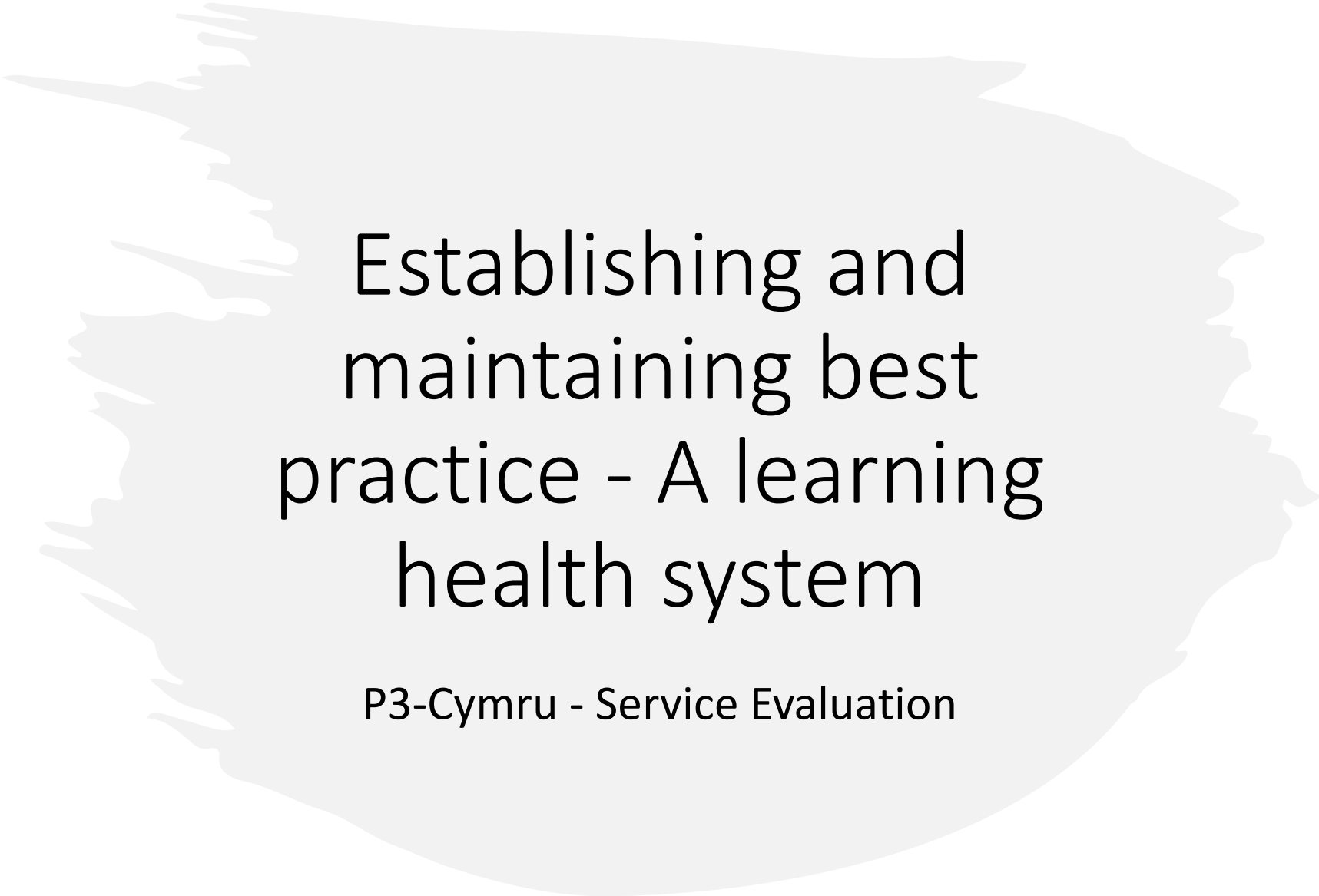
Co-presented at conferences, webinars, events



Management of social media accounts



Input on reports and scientific articles



Establishing and maintaining best practice - A learning health system

P3-Cymru - Service Evaluation

Settings/P3-Cymru

- The service is currently based at the University Hospital of Wales, and it caters to approximately 150 children and young people.
- The service plans to extend to a community-based format, which will cover an additional 300 families.

P3-Cymru - Service Evaluation

- Ongoing collaboration with Dr. Wilkinson and his implementation team
- Evaluation is planned but not yet formally underway
- Aiming to understand the impact and guide future service development

Our main goal

What helps a new children's chronic pain service work — for whom, in what settings, and how?

How we will evaluate the service



REALIST EVALUATION



DATA FROM DIFFERENT SOURCES



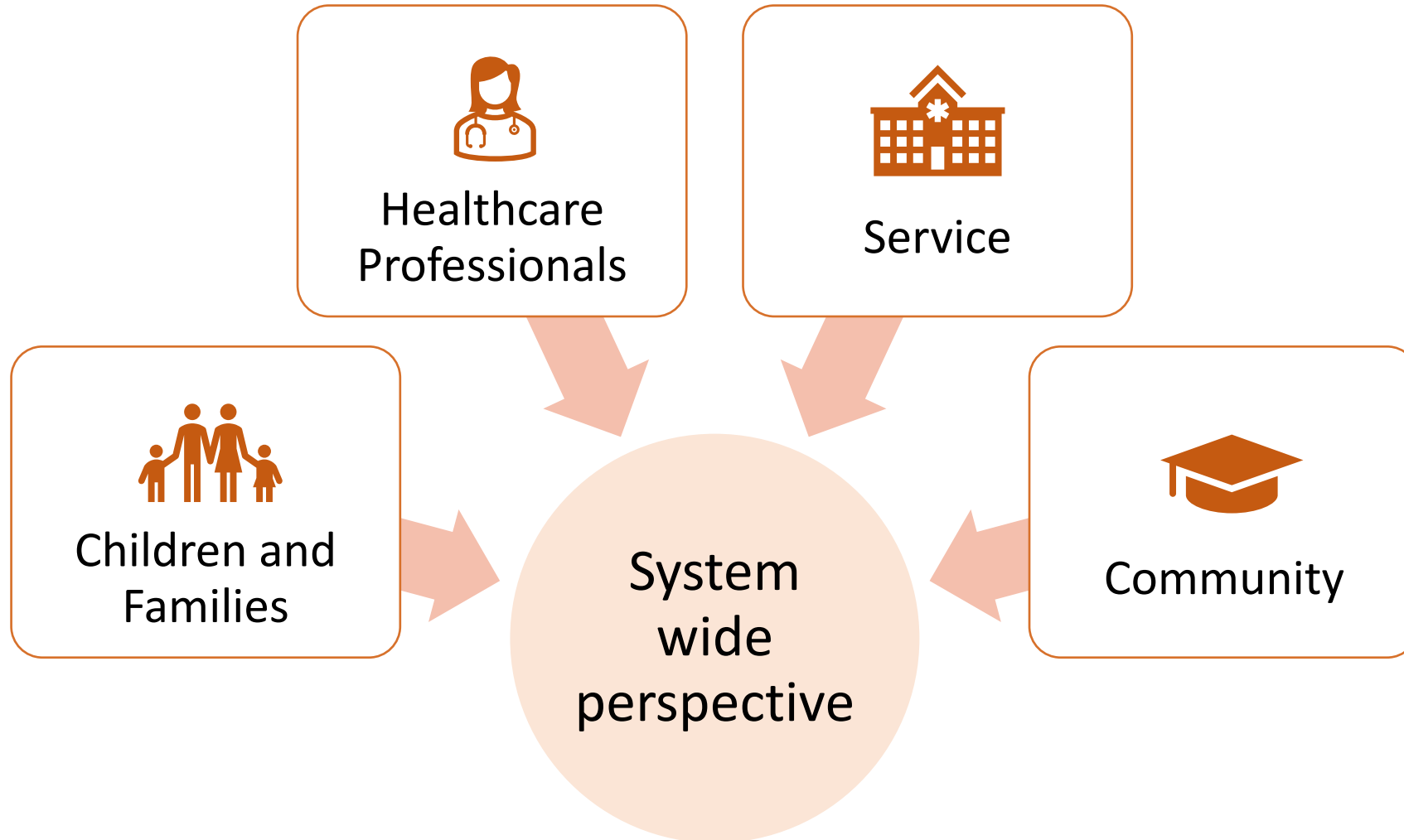
COLLABORATIVE APPROACH
INVOLVING PATIENTS, THE
PUBLIC AND KEY STAKEHOLDERS
AT ALL STAGES



Co-production

- **The evaluation will involve** children and adolescents (8 - 18 years) and their families, patient groups and third-sector organisations, along with other relevant stakeholders

What Works for whom...



Data Collection Overview

Interviews:

- *People delivering the service (e.g. staff, healthcare professionals, school staff)*
- *Children, young people & families*

Quantitative Data:

- Routine service data and population level data
- An online survey (at two time points) with children, families, and staff

Qualitative Interviews



HOW, WHY, WHEN, AND WHERE THE SERVICE WORKS (OR DOESN'T)



WHAT DIFFERENT PEOPLE THINK AND EXPERIENCE



WHETHER IT'S ACCESSIBLE AND REALISTIC FOR FAMILIES



FAMILIES AND STAFF NEEDS ARE BEING MET

Quantitative Administrative Data



Data Sources:



Secure Anonymised Information Linkage (SAIL) Databank



School networks and administrative data sources



Questionnaire data



Data Types:



School attendance records

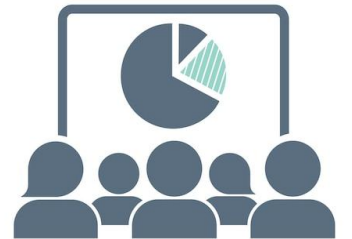


Administrative patient data

Administrative & Routine Data

We'll collect information about each child:

- Age, background, and family situation
- Pain and how it affects them
- School attendance and academic progress
- Quality of life and wellbeing
- Use of healthcare services





Administrative & Routine Data

Data from large databases

- Use graphs to show how things change for children and families over time
- Compare differences for individuals
- Compare different groups
- Create **simulated comparison groups** to see what might have happened without the service

Costing and Resource Use

- The total cost to run the service
- The cost of care for each person

Tracking resources used — staff time, medication, and equipment

We'll use **trusted sources** to find current prices, such as:

- *Personal Social Services Research Unit (PSSRU)* – for health and social care costs
- *British National Formulary (BNF)* – for medication prices



Making Sense of What Works



We'll check which parts of the service seem to work, for whom, and why — using all the data we've collected.



We'll compare: What was planned with what actually happened.



Findings will help guide successful rollout across the country.



Families and key stakeholders will help us shape and test these ideas to make sure they're meaningful and relevant.

How research informs and improves health services: The Learning Health System



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Thank you!



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Why not join the Association of British Paediatric Nurses?

Invest in the future of children's nursing by joining the ABPN

The ABPN is a network of children's nurses working in any setting and speciality, including clinical practice, education, leadership and research

We are the oldest children's nursing association in the world, established in 1938

Help to influence nursing care and services for infants, children and young people

Check out our activities and campaigns at www.abpn-uk.com and get involved

