



The Association
for Child and Adolescent
Mental Health

Tuesday 28th March
Starts at 17.00 pm

Stress, adversity, COVID; caring for children with an intellectual disability

The *sixth* of ACAMH's Adverse Childhood Experiences (ACEs) Special Interest Group Monthly seminars.

- 17.00** **Welcome to the event & introduction** - Dr Arnon Bentovim, Child and Family Psychiatrist and Director of Child and Family Training
- 17.20** **Stress, adversity, COVID; caring for children with an intellectual disability –**
Dr Jeanne Wolstencroft, Research Fellow at the Great Ormond Street UCL
Population, Policy and Practice Dept
- 18.20** **Q&A**, Led by Dr Arnon Bentovim, Child and Family Psychiatrist and Director of Child
and Family Training
- 18.45** **Close** - Dr Arnon Bentovim, Child and Family Psychiatrist and Director of Child and
Family Training



Stress, adversity, COVID; caring for children with an intellectual disability

Dr Jeanne Wolstencroft

Research Fellow

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28th March 2023, ACAMH

Agenda

- Setting the scene: IMAGINE



Agenda

- Setting the scene: IMAGINE
- Interview study during Covid-19



Agenda

- Setting the scene: IMAGINE
- Interview study during Covid-19
- Impact of Covid-19 on IMAGINE cohort



What is IMAGINE?

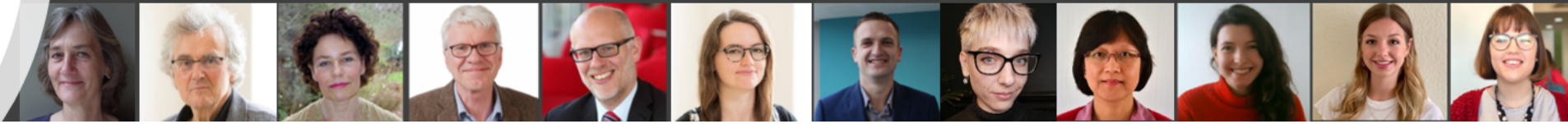


IMAGINE PROGRAMME

Funded by Medical Research
Council & Medical Research
Foundation

IMAGINE-1: 2014 - 2019

IMAGINE-2: 2020 - 2024



IMAGINE ID Cohort

2,809 children



Children aged 4 – 19



learning disability or
developmental delay



Pathogenic CNV or SNV



NHS Regional Genetic Centre
recruitment



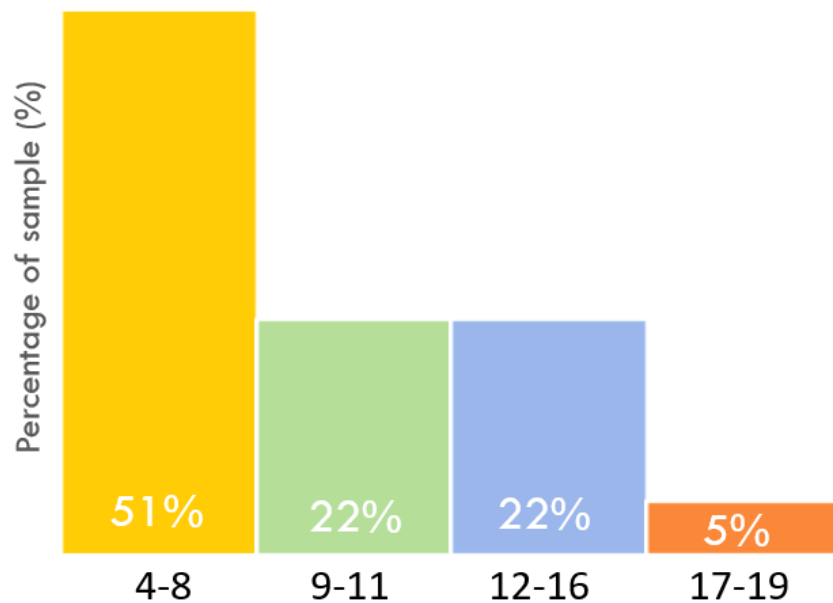
Online Assessment Completion



2,397 CHILDREN

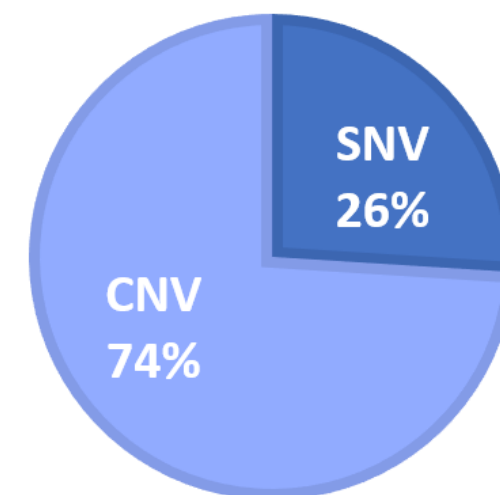


56% male

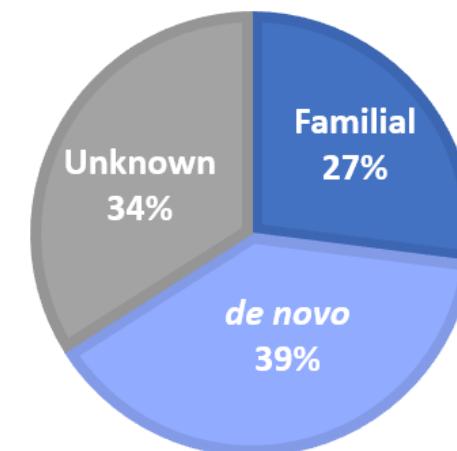


GENETICS

Type of genetic condition:



Inheritance of change:





Physical health

94% 1+ significant physical health problem

30% history of seizures

65% disturbed sleep

What are the mental health needs of children with learning disability?

Strengths and Difficulties Questionnaire



Mental health conditions

1 in 10 Anxiety

1 in 10 Behavioural problems

1 in 5 ADHD

1 in 3 Autism

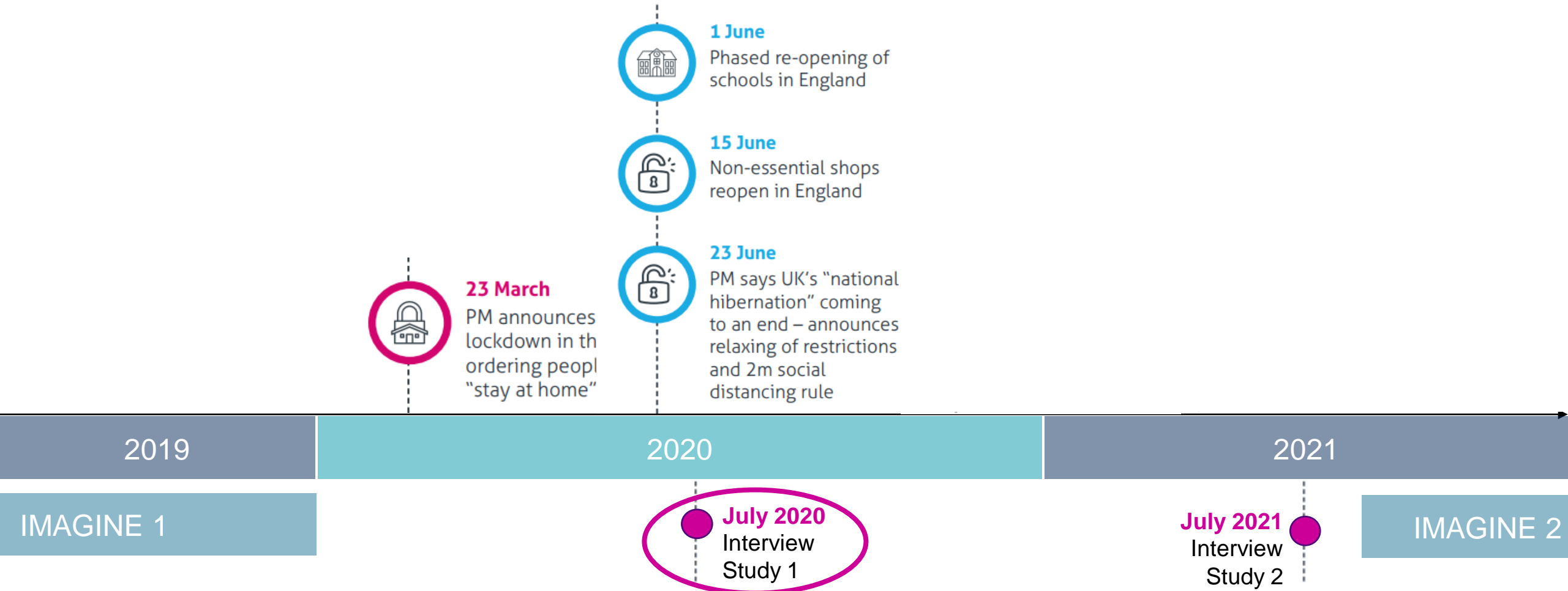


Neuropsychiatric risk in children with intellectual disability of genetic origin: IMAGINE, a UK national cohort study

The Lancet Psychiatry

Covid-19 Interview Study

Timeline





AIMS

Explore the experiences of parents of children with an Intellectual and Developmental Disability (IDD) and a rare genetic disorder during the COVID-19 pandemic.

PARTICIPANTS

- IMAGINE Study Participants
- 23 mothers
- 14 boys and 9 girls aged 5–15 years

METHODS

- Mixed methods: Online survey + Telephone interviews
- Thematic analysis

Online Survey (n=23)

Coronavirus Health and Impact Survey (CRISIS)

Family circumstances, distress and resilience
during the pandemic (parent report)

COVID IMPACT



of families were shielding



87% reported that restrictions on leaving home had been stressful for their child



reported the family had difficulty following the government recommendations



reported that their child's school had been closed



reported that the pandemic had reduced their ability to earn money





PARENT MENTAL HEALTH



A quarter of parents
reported anxiety
symptoms

CHILD WORRIES



of children were reported
to be worried about getting
infected with COVID-19



were concerned about their
physical health

UNEXPECTED POSITIVES

74%

families reported at least one positive change as a result of
the pandemic



Telephone Interviews



Thematic Analysis

Transcribe

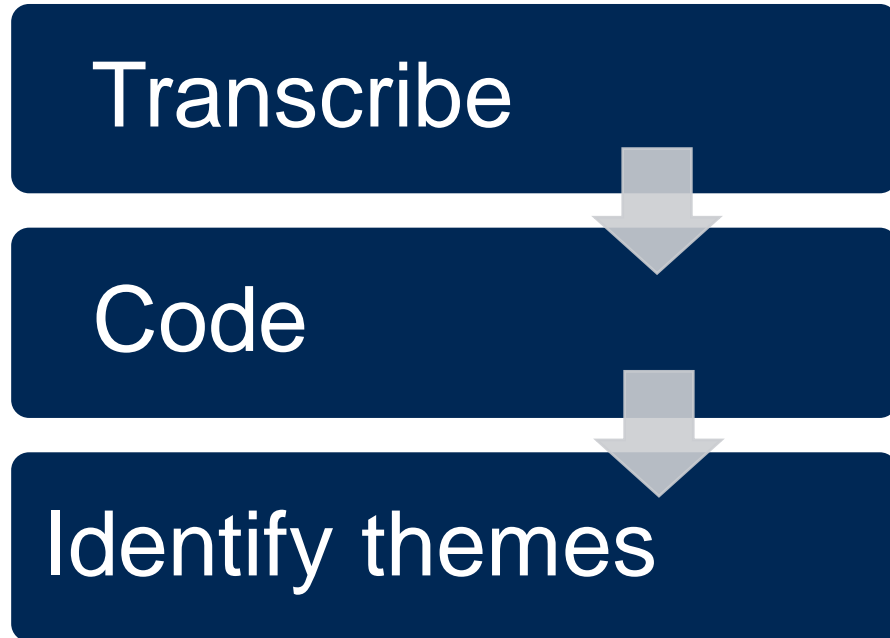


Code



Identify themes

Thematic Analysis

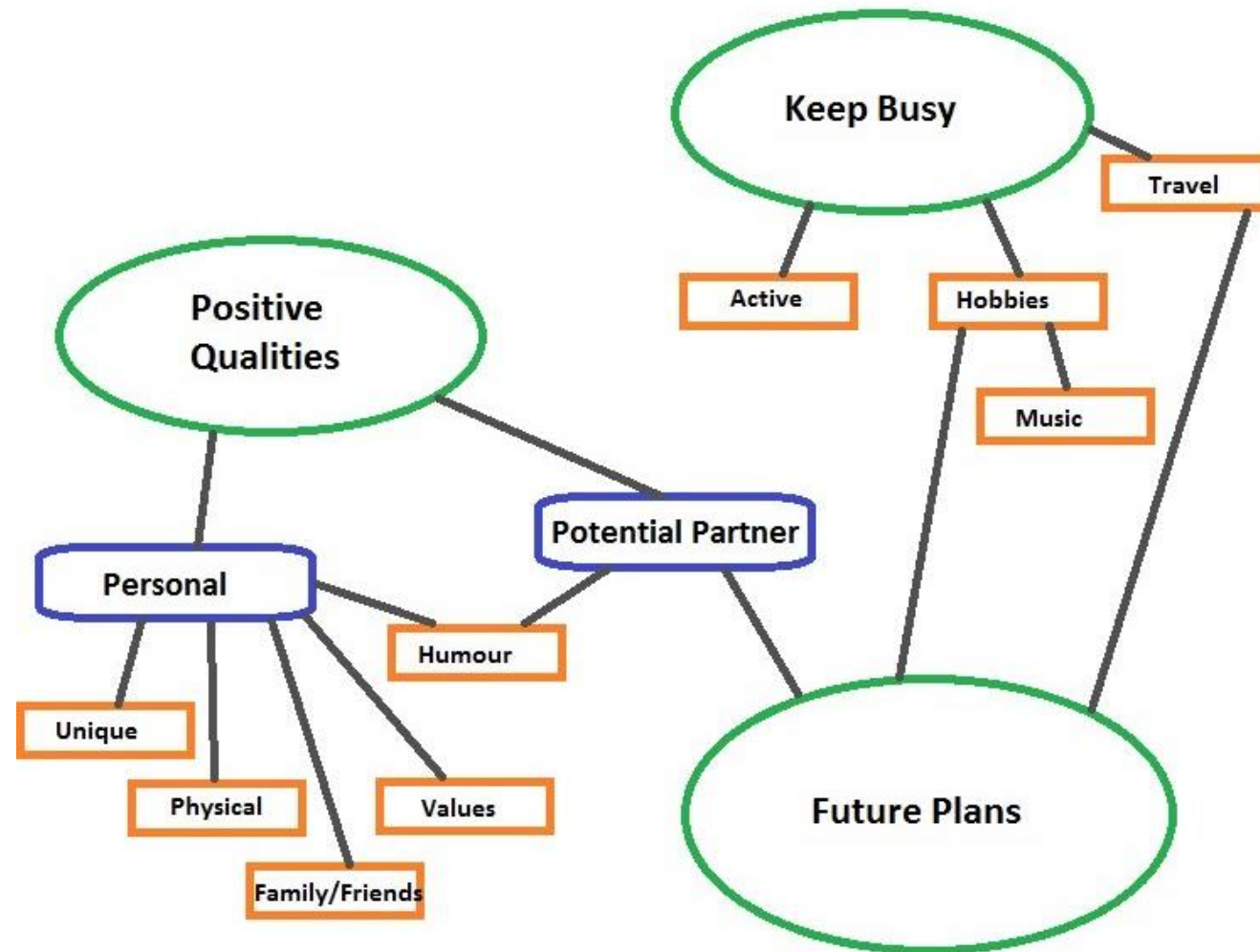


I am tall, single (widowed), easy going, honest, good listener with a good sense of humour. Being a handyperson I keep busy working around the house, I also like to follow my favourite hockey team on TV or spoiling my two granddaughters when I get the chance!! I enjoy most music except Rap! I keep fit by jogging, walking and bicycling(at least three times a week). I have travelled to many places and RVd the South West U.S., but I would now like to find that special travel partner to do more travel to warm and interesting countries. I now feel its time to meet a nice, kind, honest woman who has some of same interests as I do; to share the happy times, quiet times and adventures together.

Thematic Analysis

Physical description	Widowed	Positive qualities
Humour	<p>I am tall, single(widowed), easy going, honest, good listener with a good sense of humour. Being a handyperson I keep busy working around the house, I also like to follow my favorite hockey team on TV or spoiling my two granddaughters when I get the chance!! I enjoy most music except Rap! I keep fit by jogging, walking and bicycling(at least three times a week). I have travelled to many places and RVd the SouthWest U.S., but I would now like to find that special travel partner to do more travel to warm and interesting countries. I now feel its time to meet a nice, kind, honest woman who has some of same interests as I do; to share the happy times, quiet times and adventures together.</p>	Keep busy
Family		Hobbies
Music		Active
Travel		Future plans
		Partner qualities
		Future plans

Thematic Analysis



Main themes

“you just feel like our life was so different to other people’s”



MANAGING
PRE-EXISTING
CHALLENGES



MIXED EMOTIONS

“The pandemic was nice but really hard”

“just being able to have that support bubble, rather than being locked in your own four walls”



SUPPORT
MATTERS

SOCIAL DISTANCING IS THE NORM

“We’ve been in lock down since he was born”

LEFT BEHIND

“I feel like they just left people who are vulnerable behind for two months.”



MANAGING PRE-EXISTING CHALLENGES

PLANNING FOR COMPLEX NEEDS

“there’s a lot more things that I needed to do than the average sort of family”

EXPLAINING COVID CHANGING

“How do you explain a pandemic?”

**FEWER RESOURCES,
BUT BEHAVIOURAL ISSUES ARE
THE SAME**

HAPPY AT HOME

“Everyone’s keeping distance from me and that’s how I like it”

SPENDING TIME TOGETHER AND SLOWING DOWN

“It brought us a lot closer together”



MIXED EMOTIONS

DESPERATE FOR HUGS

“I don’t like lockdown because I want snuggles with my nanny”

STRAINED RELATIONSHIPS

“Being constantly 24/7 together definitely did build up pressure”



TRANSITION TO TELEHEALTH

“I don’t think you can replace face to face with a telephone”

CHECKING IN

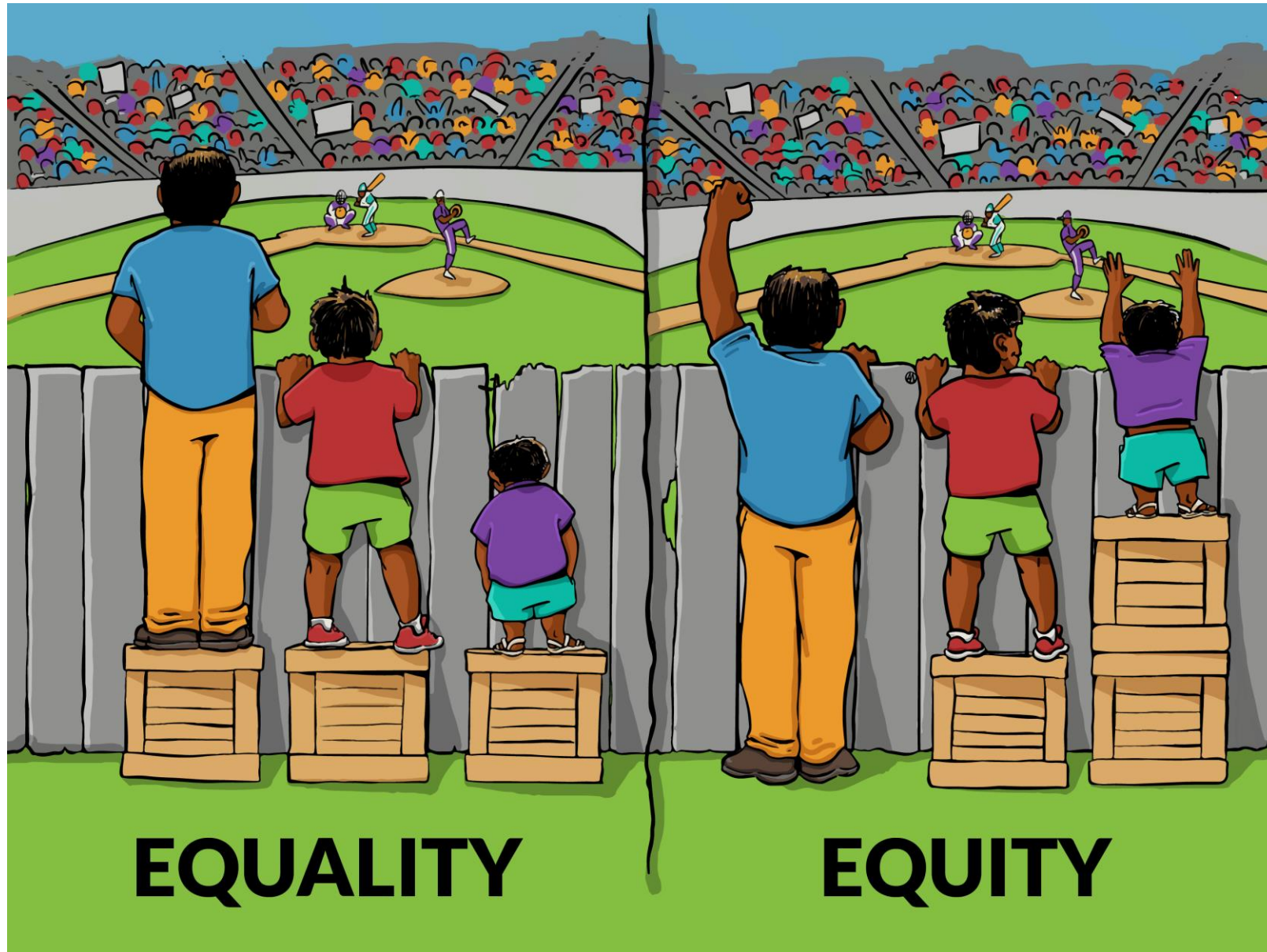
“just being able to have that support bubble, rather than being locked in your own four walls”

EQUALITY THROUGH ACCESS TO TECHNOLOGY

“I think the first thing to do is make sure everyone is able to access what they’re providing”

EQUITY OF ACCESS LAGGING BEHIND AS ADAPTATIONS AREN’T ALWAYS APPROPRIATE

“That is very difficult to do when you have special needs”



TRANSITION TO TELEHEALTH

“I don’t think you can replace face to face with a telephone”

CHECKING IN

“just being able to have that support bubble, rather than being locked in your own four walls”



SUPPORT MATTERS

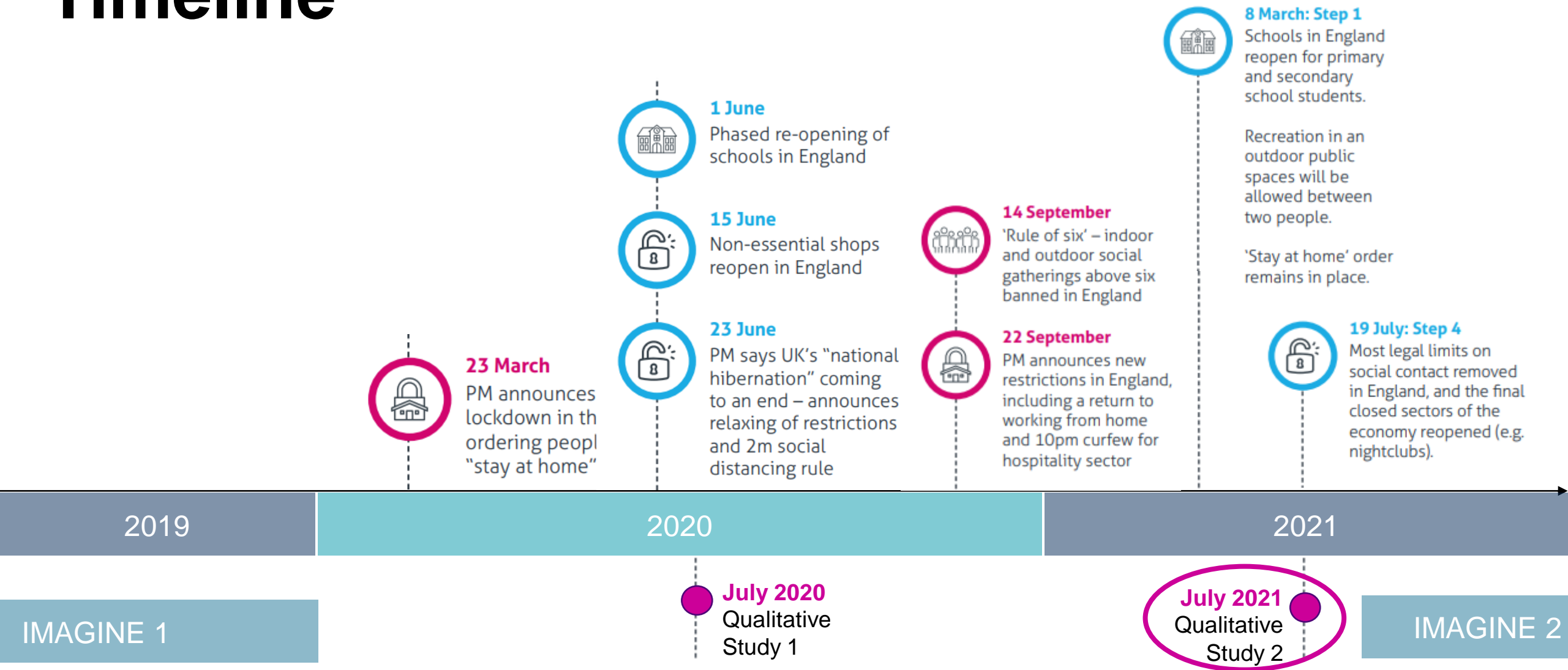
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Timeline

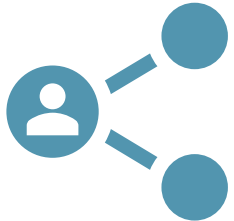


July 2021: New themes



Anxiety returning
to school

“He was really anxious to start off. He was getting upset every morning because (...) he had to go to school”



Functional and
social skills concerns

“He hasn’t got any siblings, so he regressed for things like sharing and waiting. I think the saving grace for us was when he went back to school.”



Academic concerns

“Undoubtedly there will have been impacts on his learning, there will gaps that I have nowhere near filled.”

Mental health and behaviour



Parental distress & resilience



Unexpected positives



Varied impact on children



Change in concerns over time:

Complex behaviour -> emotional wellbeing & development



School and healthcare



Short but regular check-ins



Digital equity

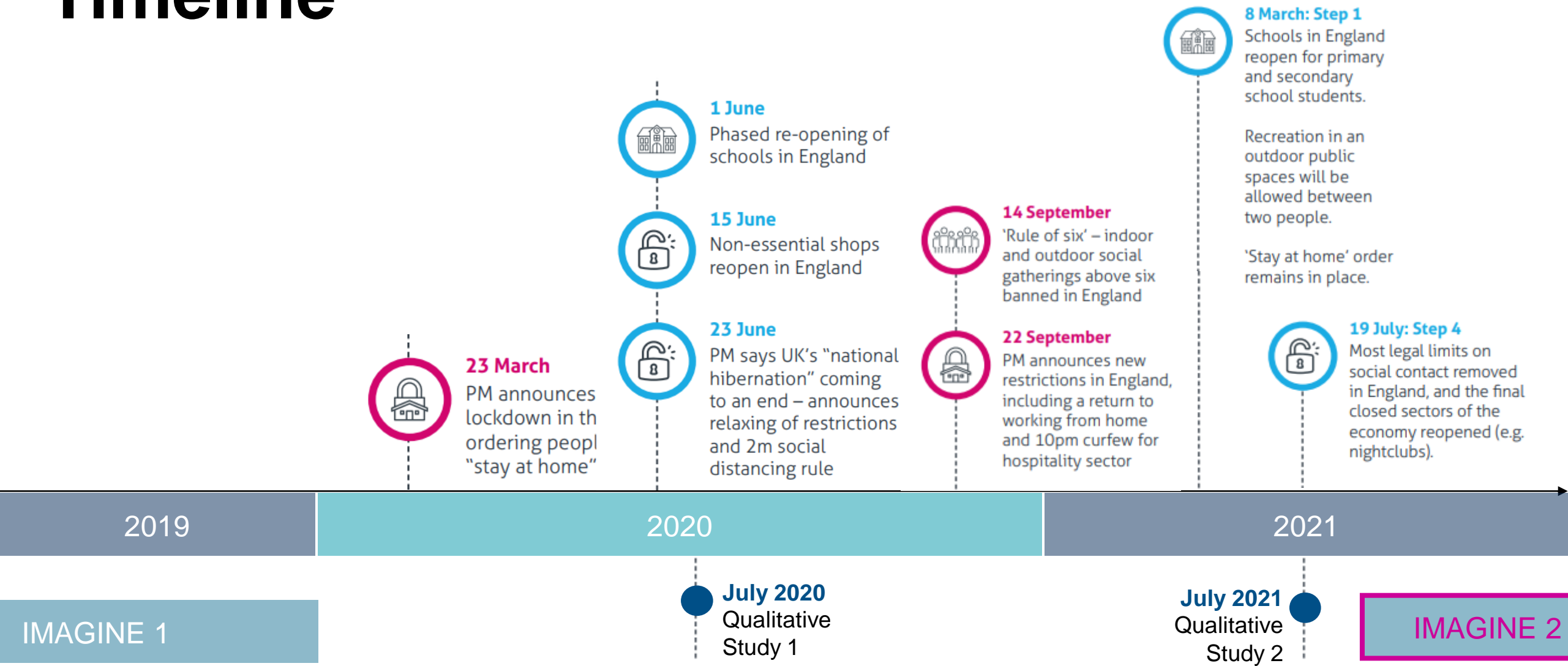


Tele-medicine as complementary care delivery

IMAGINE 2: Online Survey

- Changes in mental health?
- Impact of Covid-19?

Timeline



May-December 2021 (n=1063)

Strengths and Difficulties Questionnaire (SDQ)

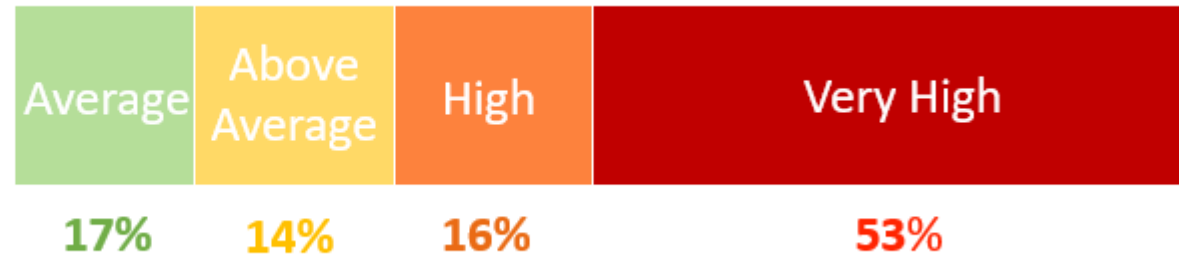
Child emotional and behavioural adjustment
(parent report)

Coronavirus Health and Impact Survey (CRISIS)

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during the pandemic (parent report)

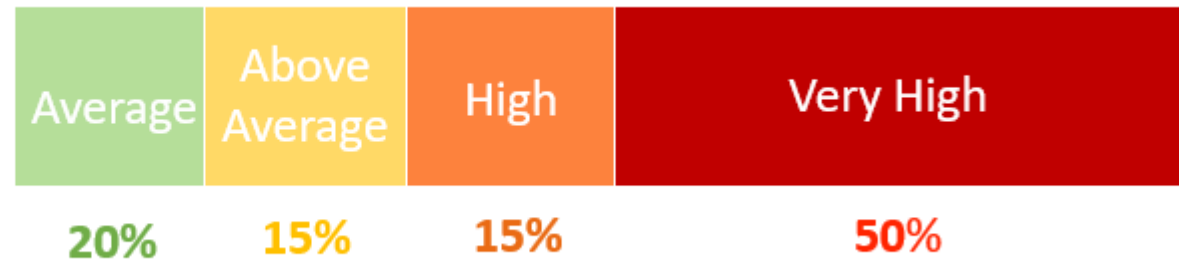
Strengths and Difficulties Questionnaire

iMAGiNE iD



Before pandemic
2014-2019

iMAGiNE 2



After lockdown
2021

Strengths and Difficulties Questionnaire

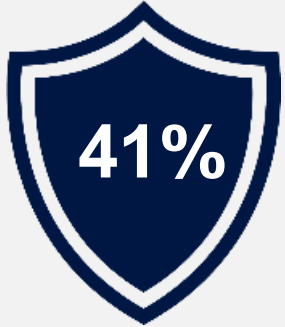
iMAGiNE iD

iMAGiNE 2

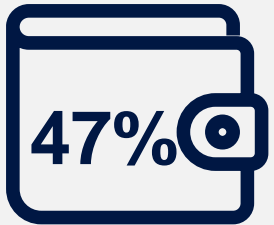


Before pandemic
2014-2019

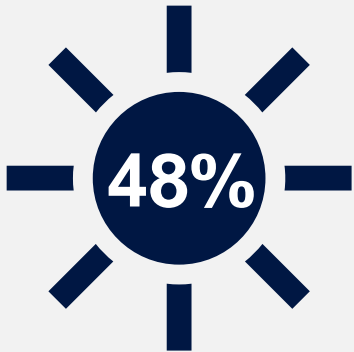
After lockdown
2021



of families were shielding

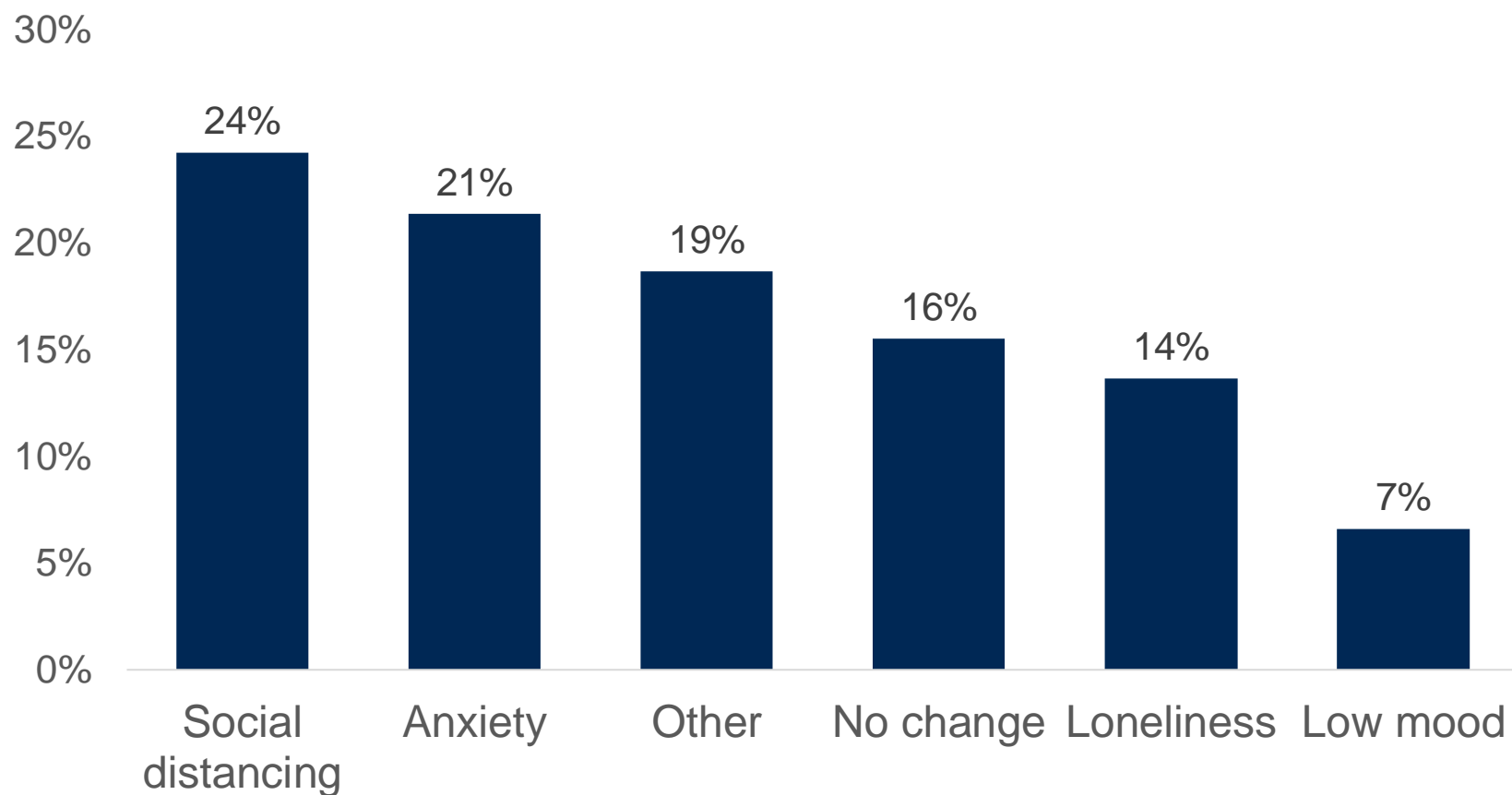


reported that the pandemic had reduced their ability to earn money



families reported at least one positive change as a result of the pandemic

Biggest challenge



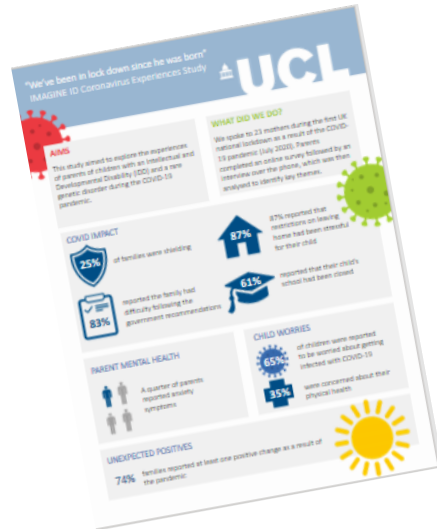
Practical implications

- Care co-ordination
 - Brief check-ins
 - Support the parent to support the child
- Tele-medicine has a role to play

Strengths and limitations

- Biases
- Confirms previous observations
- New insights:
 - use of technology during the pandemic for schooling and healthcare
 - need for regular check-ins

Thank you for listening!



<https://imagine-id.org/news/coronavirus-experiences-study-findings/>

<https://bmjopen.bmj.com/>

Questions:

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Questions?