HOW WE ARE USING YOUR RECORDS IN CHILDREN OF THE 90S:

INVESTIGATING SELF-HARM, DEPRESSION, AND ROAD SAFETY BEHAVIOURS AND ACCIDENTS

20 JULY 2016

CHILDREN OF THE 90S

University of BRISTOL

Avon Longitudinal Study of Parents and Children

Supported by wellcome trust

MRC Medical Research Council

RECORD LINKAGE: A BRIEF SUMMARY

WHAT IS RECORD LINKAGE?

- ‘Record linkage’ is the technical process whereby separate records (data sources) belonging to the same individual are identified and brought together (linked).

- In the context of Children of the 90s, this is done so that the linked information can be used in a research investigation.

THE RECORD LINKAGE PROCESS

1. We gain the required authorisations to access study participants records
2. We agree a set of information security standards and enter into a legally binding contract (containing ‘rules’ about how data are used and how personal data are protected)
3. Children of the 90s and the organisation who holds the records (e.g. the NHS) both process a file of personal details (e.g. name, address, date of birth and ID numbers such as NHS ID)
4. These details (with no other information attached) are then compared by a computer program (and sometimes a person) to identify whether or not they are the same person
5. Once ‘linked’, the personal details are replaced by a meaningless ID number (like the C90s ‘barcode id’)
6. The organisation who holds the records then sends the data securely to Children of the 90s who link it with questionnaire/focus clinic data
7. This combined data is then processed to preserve confidentiality and provided to approved researchers for use in their investigations

RECORDS CHILDREN OF THE 90S ARE LINKING TO: *

Health records

- General practice records
- Hospital records
- Birth, death and cancer registry records
- NHS contact details (to help find families we have lost touch with)
- Maternity records

Education records

- School records (exam results and other school and pupil information)
- Further education & apprenticeship records
- Higher education records

Environmental & geographical

- Neighbourhood information
- Pollution data
- Traffic data

* This is not a complete list of ongoing linkage work and not all participants are linked to these records

INFORMING YOUR CHOICE

Information pack (currently young people only)

- Describes how we would like to use your records
- Form – allowing you to record your decision
- Available online as well as sent to home address

http://www.bristol.ac.uk/alspac/participants/young-people/

Keeping you informed

- Describe the specific research projects using your data

http://www.bristol.ac.uk/alspac/researchers/research/proposals/

http://www.bristol.ac.uk/alspac/participants/young-people/

- Newsletters

http://www.bristol.ac.uk/alspac/participants/newsletter/

Your right to object

- If you do not want your records used then please tell us: alspac-linkage@bristol.ac.uk or **0117 33 10010** or **by post**

LETTING US KNOW YOUR DECISION

What happens if you say yes to linkage?

- We note this decision and then start to (securely) collect and process your records.

What happens if you say no to one, some or all linkage options?

- We note this decision and do not link to your routine records.

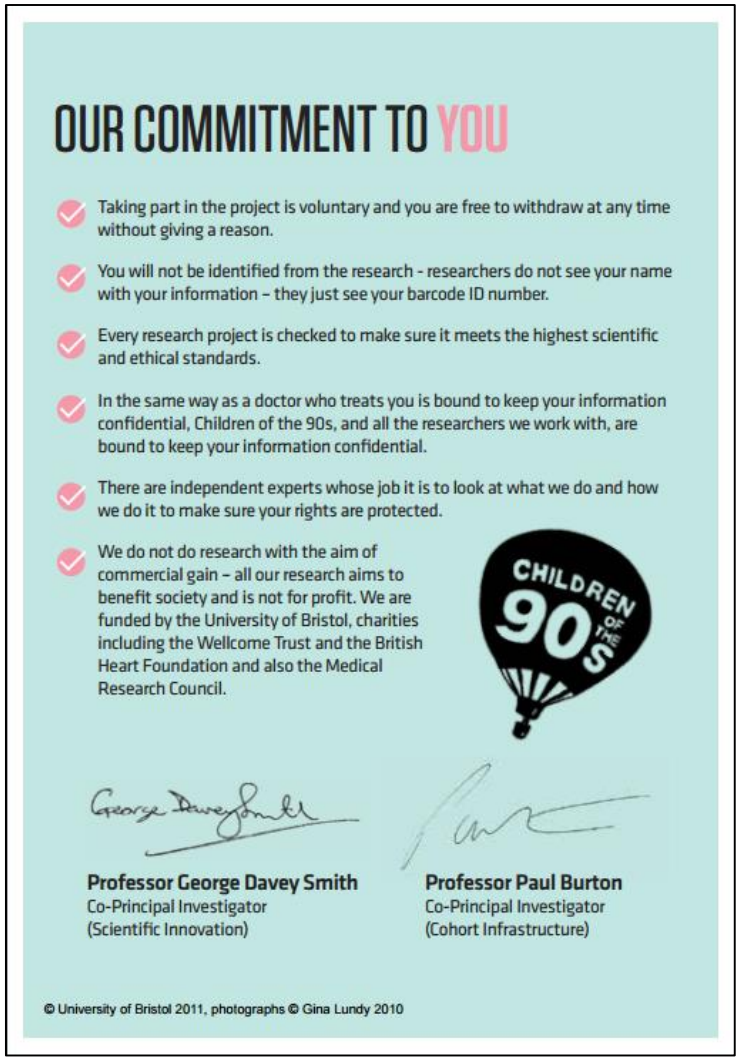
What happens if you do not send back the consent form?

- Where our research is in the public interest we may be allowed to use information from your records. This is important, as the research we do has more value (and in some cases is only possible) when as many people are included as possible.

Changing Your Mind

- You are free to change your mind at any time. Get in touch with the study and we will keep a record of your decision and explain what happens next.

OUR COMMITMENT TO YOU



OUR COMMITMENT TO YOU

- Taking part in the project is voluntary and you are free to withdraw at any time without giving a reason.
- You will not be identified from the research - researchers do not see your name with your information – they just see your barcode ID number.
- Every research project is checked to make sure it meets the highest scientific and ethical standards.
- In the same way as a doctor who treats you is bound to keep your information confidential, Children of the 90s, and all the researchers we work with, are bound to keep your information confidential.
- There are independent experts whose job it is to look at what we do and how we do it to make sure your rights are protected.
- We do not do research with the aim of commercial gain – all our research aims to benefit society and is not for profit. We are funded by the University of Bristol, charities including the Wellcome Trust and the British Heart Foundation and also the Medical Research Council.

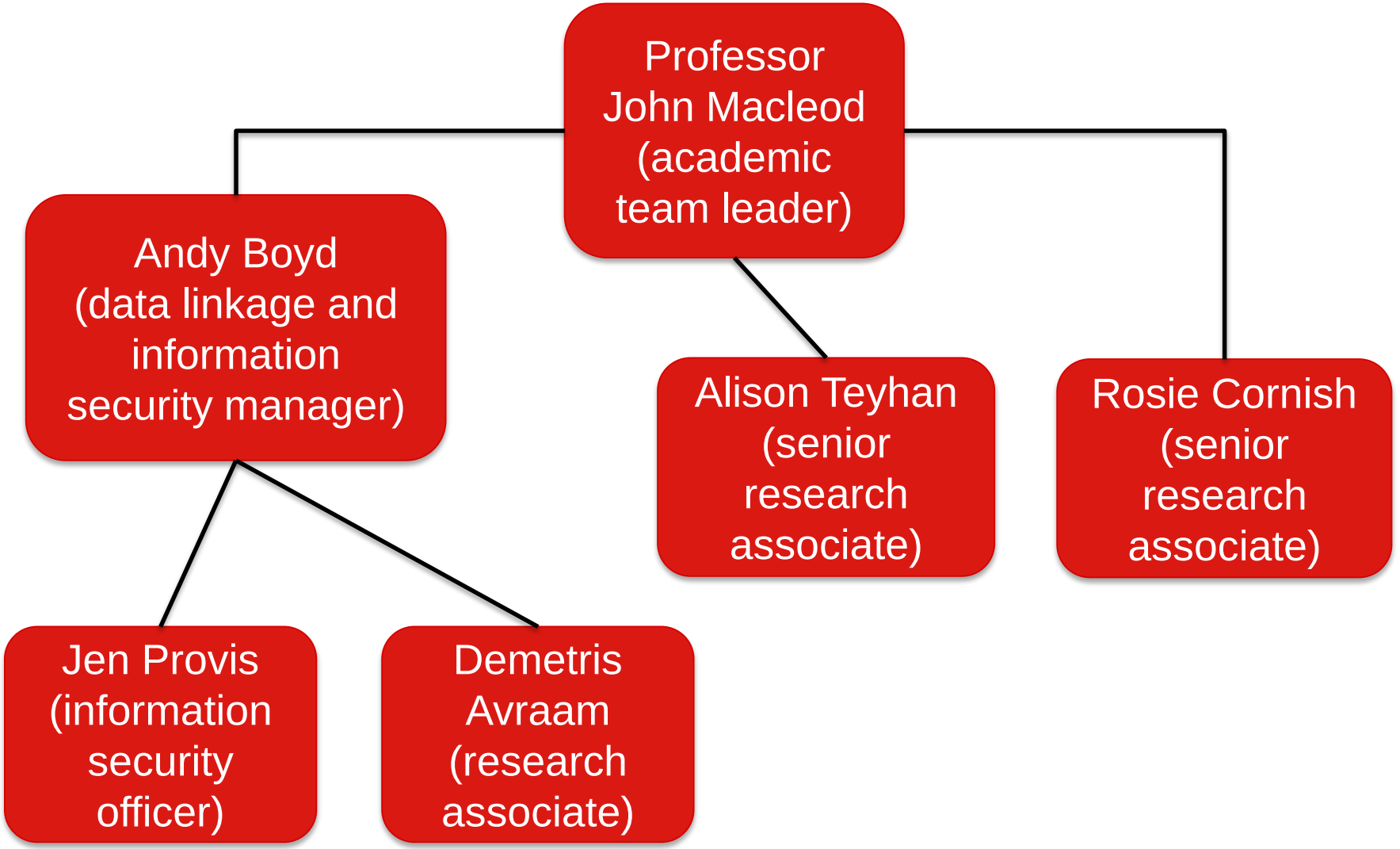
CHILDREN OF THE 90S

Professor George Davey Smith
Co-Principal Investigator
(Scientific Innovation)

Professor Paul Burton
Co-Principal Investigator
(Cohort Infrastructure)

http://www.bristol.ac.uk/alspac/participants/young-people/

THE DATA LINKAGE TEAM



Self-harm and hospital attendance: how we are using your records in Children of the 90s research

Dr Becky Mars

Children of the 90s

University of Bristol

Avon Longitudinal Study of Parents and Children

Supported by wellcome trust

MRC Medical Research Council

What is self-harm?

"Intentional non-fatal self-poisoning or self-injury, irrespective of degree of suicidal intent or nature of other types of motive"

Includes, for example:

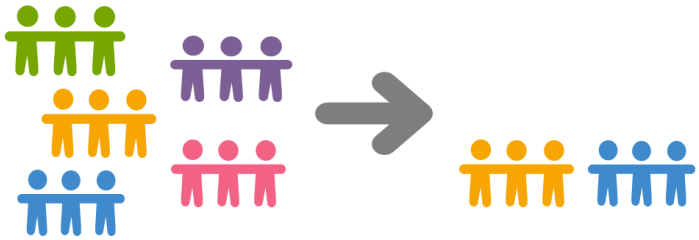
- Overdoses
- Self-cutting
- Attempted hanging
- Jumping from high places/in front of moving vehicle

Common in adolescence

Background:

- Information collected in studies like CO90s allows us to estimate how common things (like self-harm) are in the population

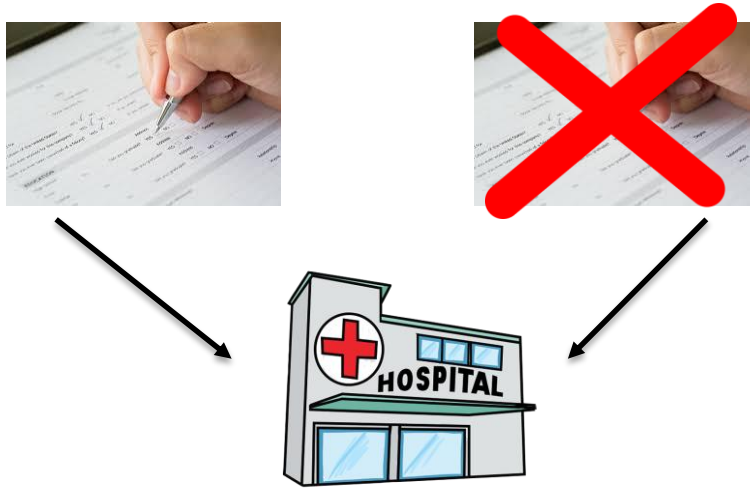
- BUT… not everybody takes part in the study at every time point:



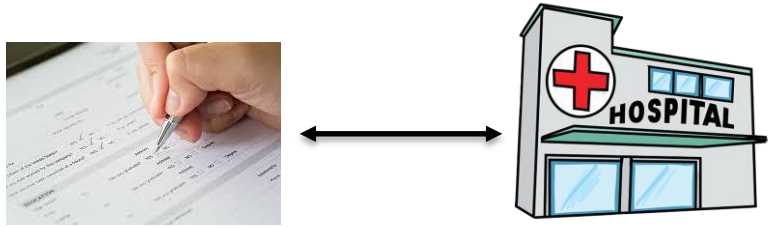
- Self-harm information is often collected via self-report:
  - Denial, reinterpretation, forgetting, current mood, misinterpretation of study questions, social desirability

Project aims:

1) Compare hospital records for self-harm and mental health issues for participants who completed the questionnaire at age 16 years and those who did not complete the questionnaire



2) Compare information about self-harm collected from participants at age 16 years to hospital records



The study sample

- 14,062 CO90s live births

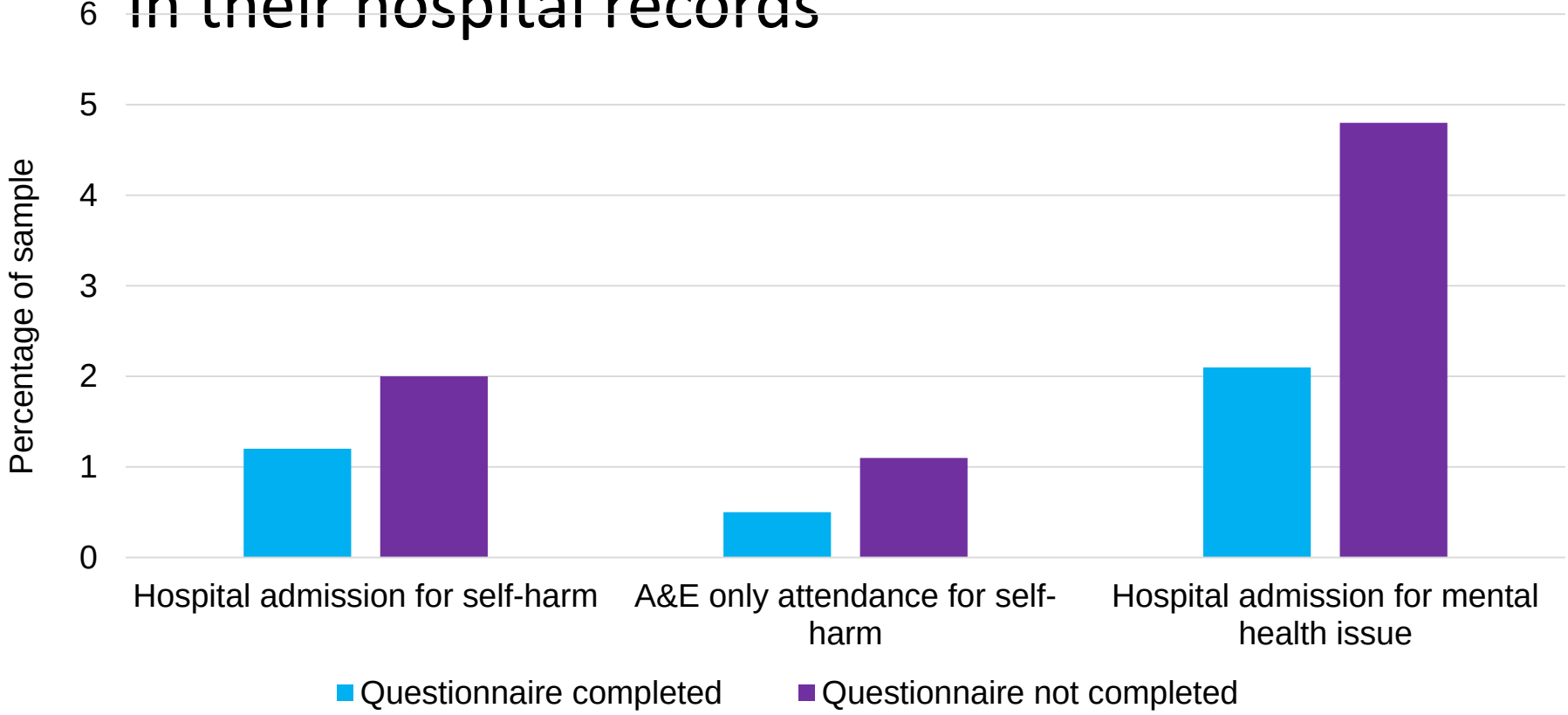
- 12,385 invited to give consent to data linkage
- 3,027 consented to data linkage with hospital records
- 371 declined to consent

- Of the 3,027 who consented, 2,363 (78%) completed the self-harm questionnaire at age 16 years. 664 (22%) did not complete the questionnaire

Results (Aim 1)

3,027 participants consented for linkage

- 54 (1.8%) had at least one self-harm event recorded in their hospital records



Results (Aim 2)

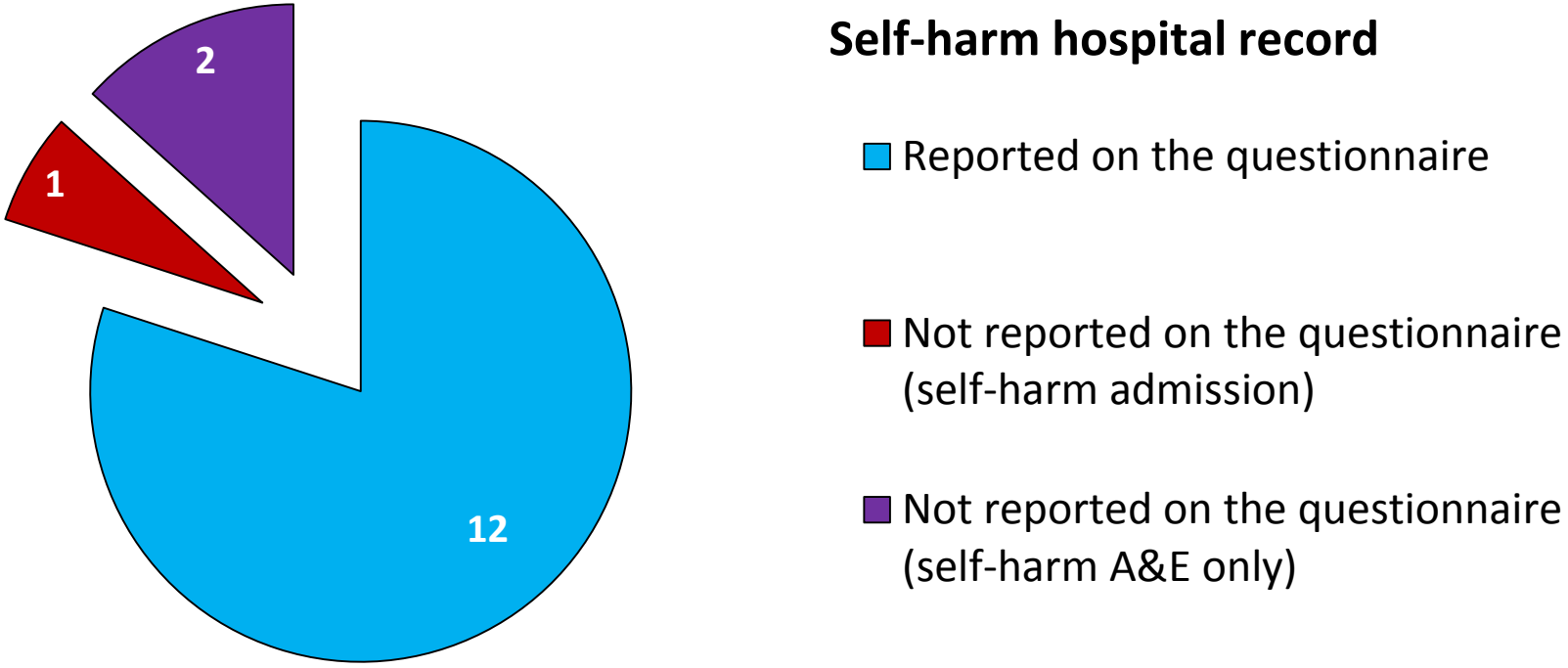
2,363 participants consented for linkage with hospital records AND completed the questionnaire at age 16 years

- 419 (17.7%) had self-harmed at some point during their lives
- 12 (2.9%) of the participants who said they had self-harmed also had a hospital record for self-harm

There were 15 participants who had a hospital record for self-harm *before* they completed the age 16 questionnaire

Results (Aim 2)

3 of the 15 hospital recorded episodes of self-harm were not reported by participants on the questionnaire



Summary:

- Hospital attendance/admission for self-harm (and mental health issues) is more common amongst those who did not complete the questionnaire

- Not all hospital recorded episodes of self-harm are reported by participants

Studies which measure self-harm via self-report (such as CO90s) may underestimate the true level of self-harm in the population

What could we look at next?

- Look at factors that predict which young people who self-harm at 16 years are most likely to be hospitalised in the future

- Extract hospital data for more participants (including those who have not responded to the consent request)
  - We have had to get special approval to do this
  - We can repeat what we have done here in a larger sample
  - We can look at factors that predict hospitalisation for self-harm, even amongst those who have dropped out of the study

Measuring depression and anxiety: how we are using your health records

University of BRISTOL

Avon Longitudinal Study of Parents and Children

Supported by wellcome trust

MRC Medical Research Council

Project aim:

To compare information about depression and anxiety collected from participants in a Focus Clinic to information from GP records

?

The data

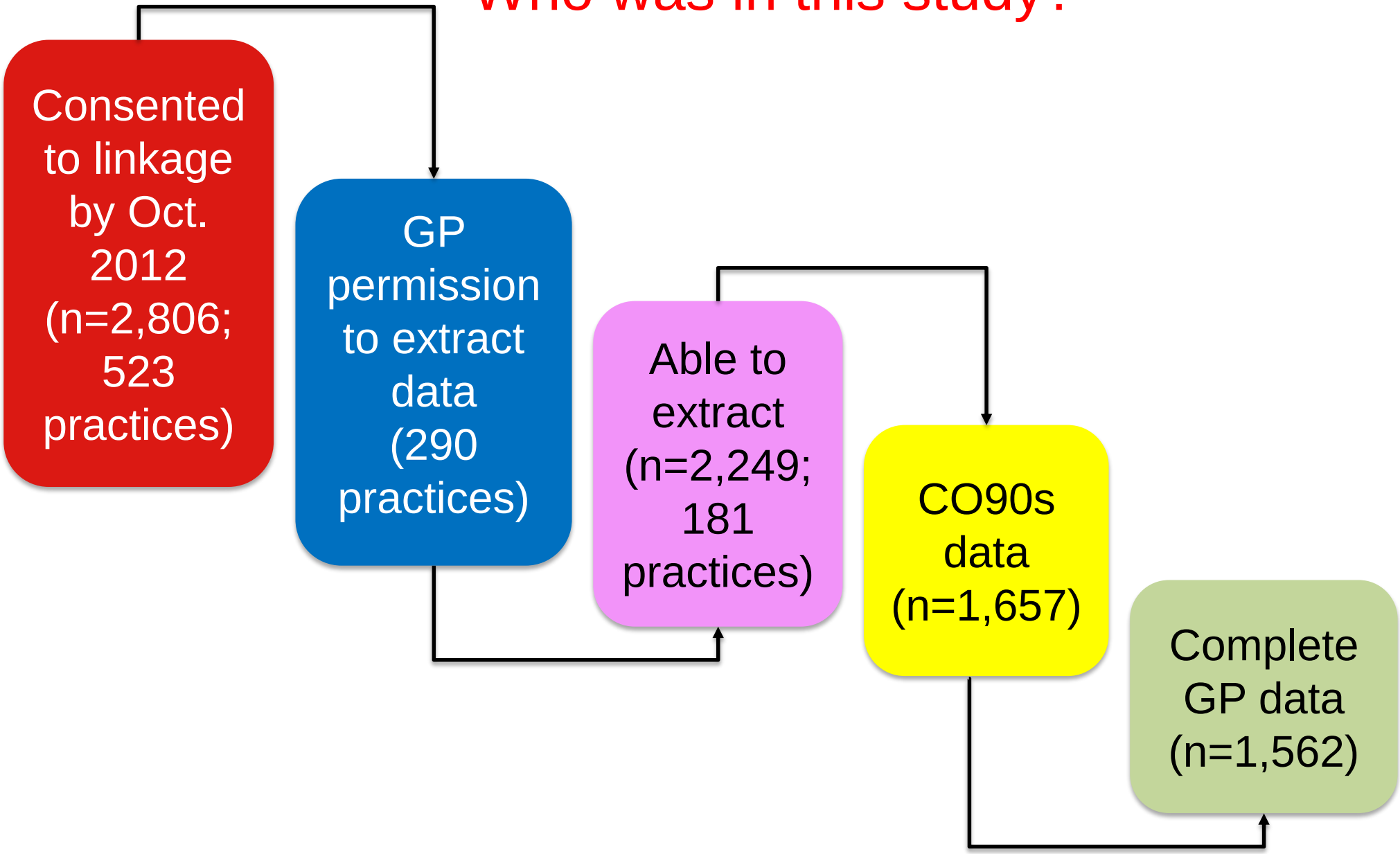
Children of the 90s data:

- Diagnosis of (1) depression (2) depression and/or anxiety disorder – from computer-based “interview” at Teen Focus 4

Linked GP data:

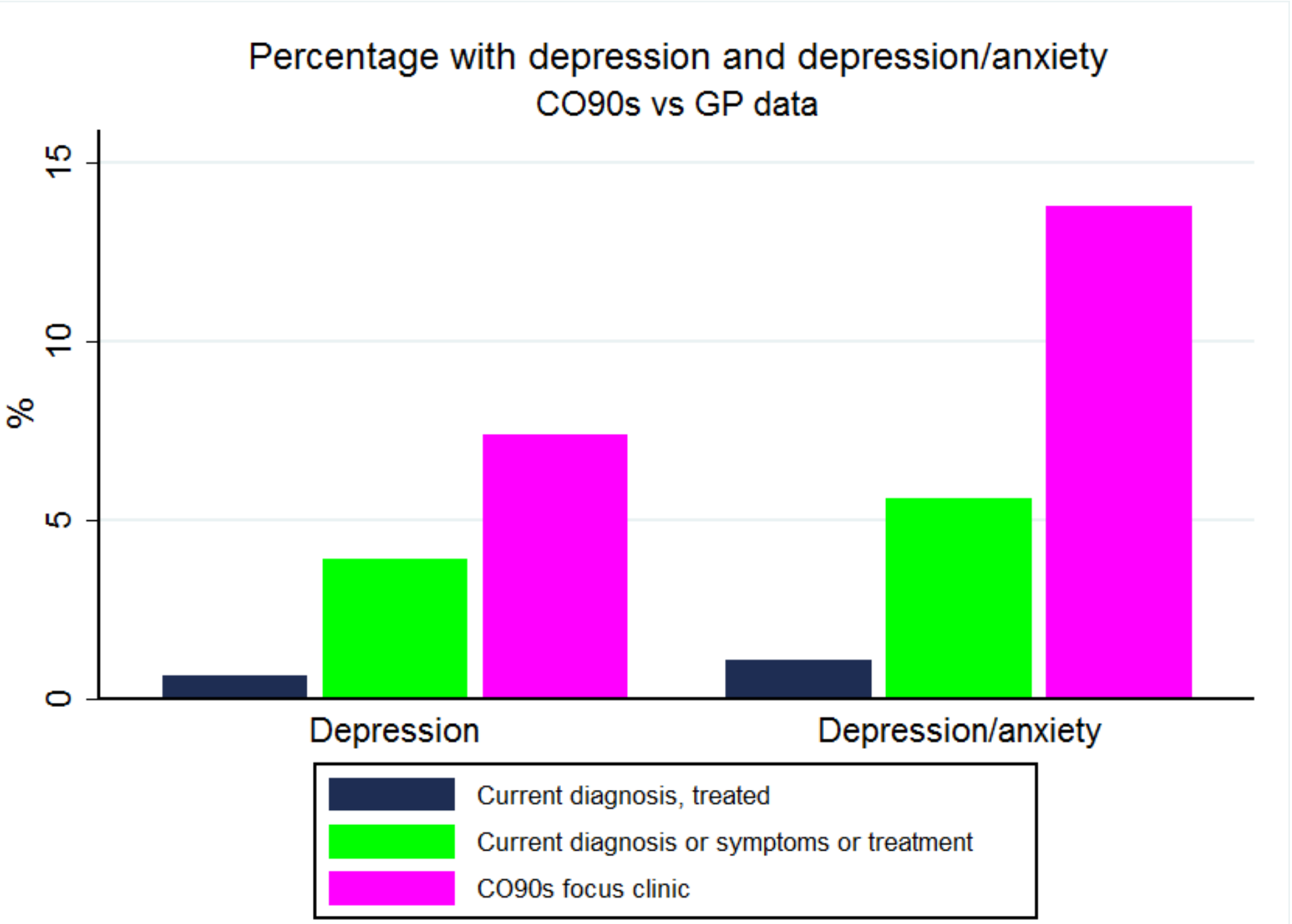
- Information about diagnoses, symptoms and treatment for depression and anxiety disorders were used to make twelve different “definitions” of (1) depression (2) depression and/or anxiety disorder.

Who was in this study?



Results

- Most participants (>98% for depression; >96% for depression/anxiety) who had depression/anxiety according to GP data were also identified as having depression/anxiety using Focus Clinic data.
- BUT… many participants who had depression/anxiety according to CO90s data had no record of this in their GP data


Percentage with depression and depression/anxiety
CO90s vs GP data
%
0
5
10
15
Depression
Depression/anxiety
Current diagnosis, treated
Current diagnosis or symptoms or treatment
CO90s focus clinic

GP definitions vs CO90s data

Graphs showing numbers who had depression/anxiety according to GP data among those who had depression/anxiety according to CO90s data.

Figure 2a: Depression

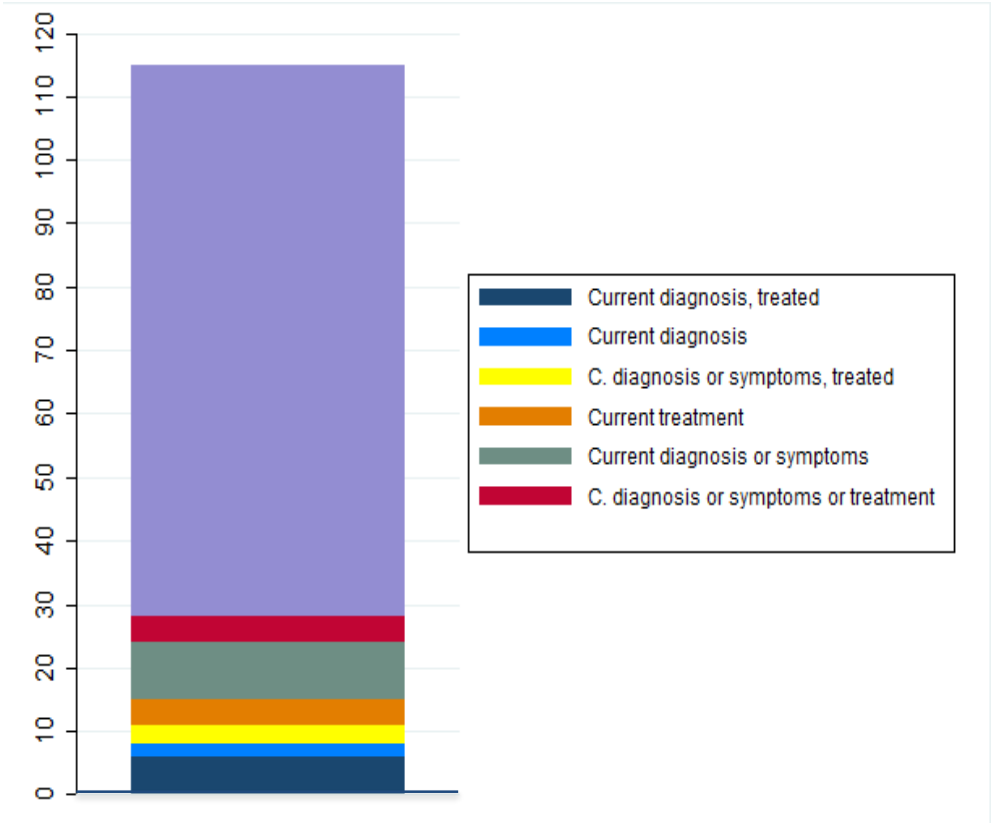
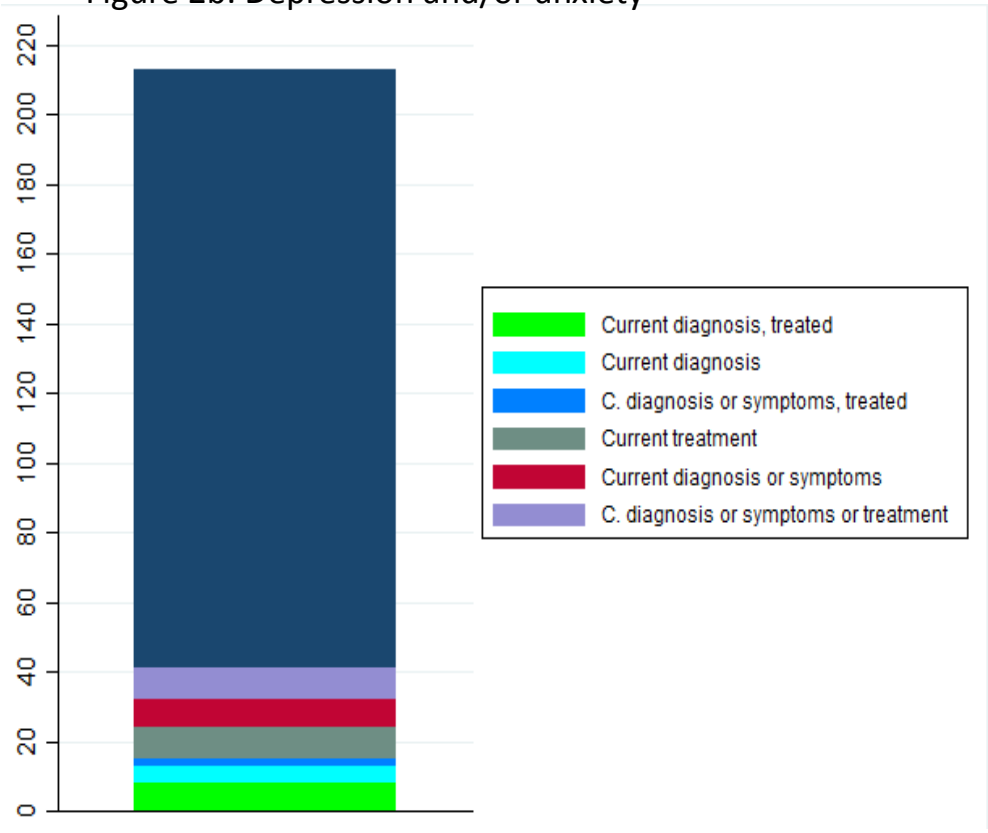


Figure 2b: Depression and/or anxiety



Summary

- Depression and anxiety are under-estimated in GP records in comparison to data collected via the Focus clinic
  - Not everyone visits a GP / reports these symptoms to their GP
  - Depression/anxiety unrecognised by GPs
  - GPs may not record it correctly
  - CO90s data may be overestimating clinical disease
- Most participants who had depression/anxiety in GP data also had depression/anxiety according to CO90s data
- Limitations in both sources of information – useful to have both

How we could use this information next

- Look at factors (e.g. sex, background) that predict whether or not a person gets a GP diagnosis

When we extract GP data for more participants (including those who did not come to the Focus Clinic):

- Combine GP data with CO90s data
- Are participants who did not attend the Focus Clinic more/less likely to suffer from depression/anxiety?
- Look at factors that cause depression and anxiety AND consequences of depression and anxiety, using data from Focus Clinic as well as GP data (able to include participants who have dropped out)

Pedestrian and cycle safety in adolescence

Using CO90s to evaluate 'Cycle Proficiency Training' and 'Lifeskills' – do they promote safer behaviours or prevent injuries?

Alison Teyhan, Senior Research Associate

Summer School, July 20th 2016

Children of the 90s
University of Bristol
Avon Longitudinal Study of Parents and Children
Supported by wellcome trust
MRC Medical Research Council

Priority to encourage active travel before and after school... and improve road safety *Public Health England, 2014*

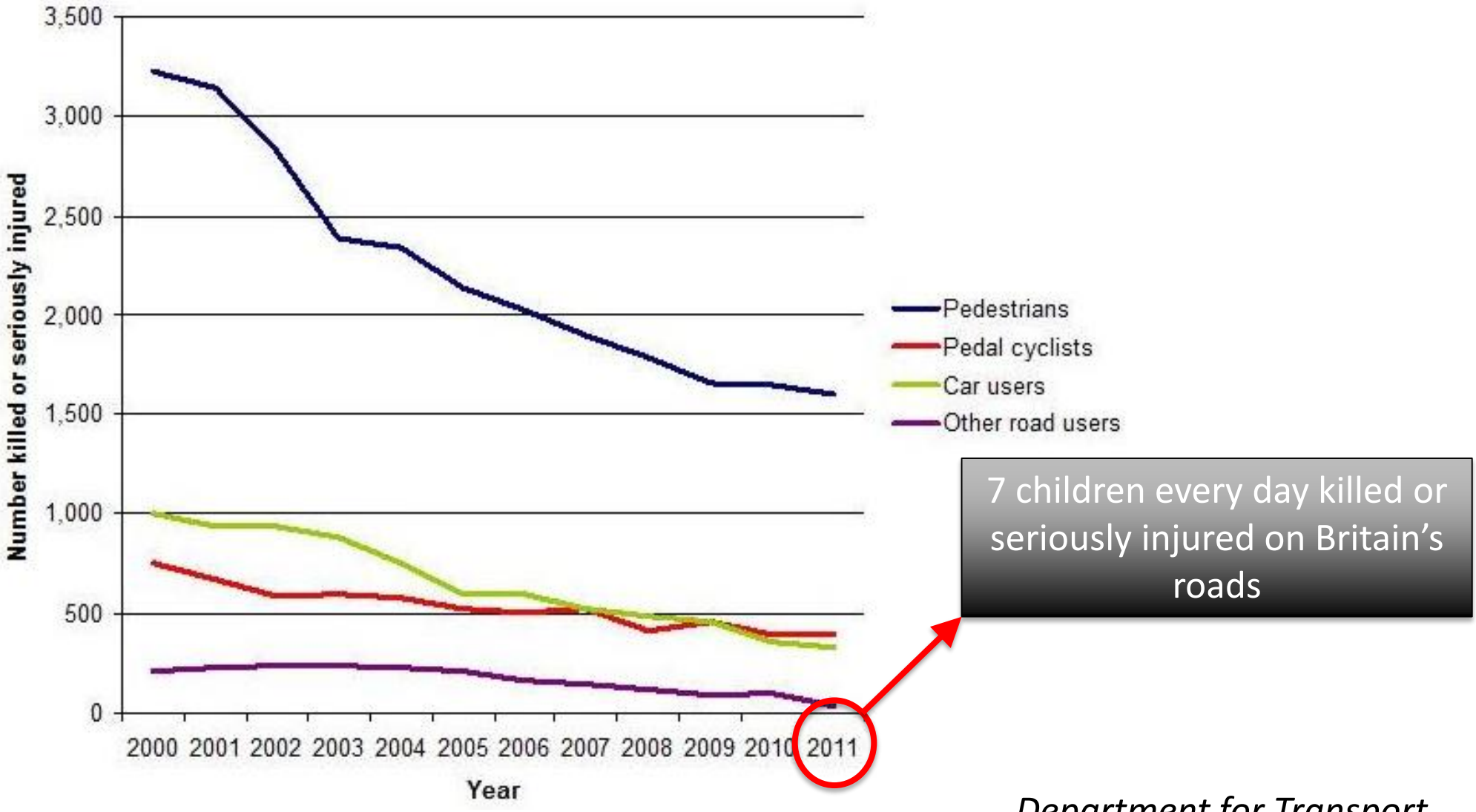
- 320,000 road casualties and 2,300 road deaths among under 25s in England, 2008-12.

- Road accidents account for over half of accidental deaths for 5-14 year olds.

- Children at most risk of being killed or seriously injured on the roads when they are on foot.

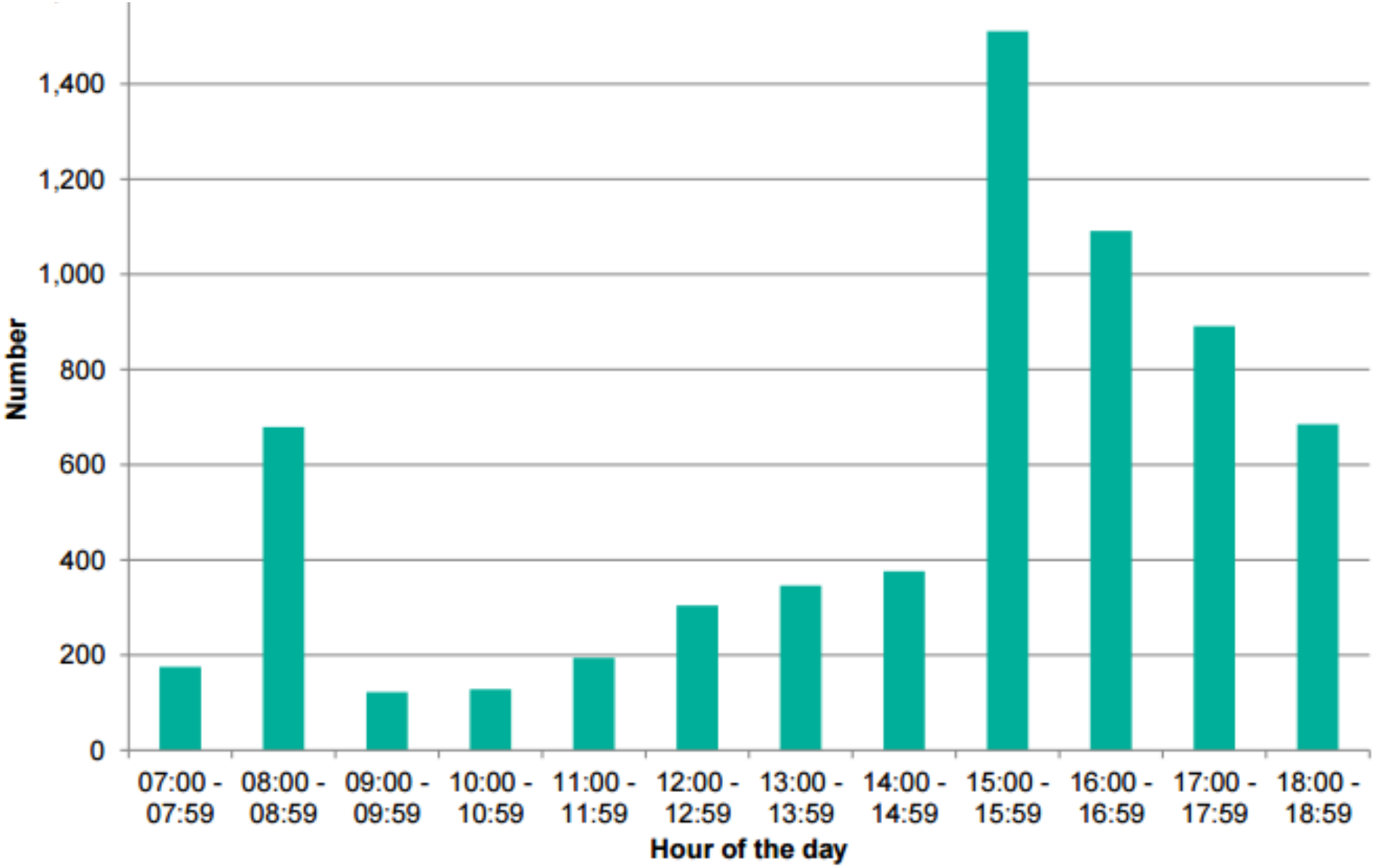
- Children 10-15yrs most at risk of cycle accidents. Almost 2000 child cyclists were injured in road traffic accidents, and 6 were killed in 2013.

Child (<16yrs) casualties killed or seriously injured by road user type



Department for Transport

Largest numbers of child (<16yrs) injuries occur between 8am to 9am and 3pm to 7pm



Education has long been regarded as important in the prevention of injuries in children and young people

But....whilst there is some evidence that education increases **safety knowledge**, evidence of whether there are subsequent **reductions in injuries or accidents** is more limited

- Lifeskills
- Cycle proficiency training scheme

Lifeskills: an interactive safety learning centre in Bristol for children aged 10-11 years

- One of 17 permanent LASER (Learning about Safety by Experiencing Risk) projects in the UK.
- Children learn not just by demonstration and discussion but by ‘doing’.
- Opened in 2000; >100,000 children have attended.
- Schools in Bristol and surrounding areas eligible to book visit for their Year 6 pupils.
- Each year, capacity for ~65% of schools to attend.

In a 2-hour visit, trained volunteer guides take small groups of pupils around the Lifeskills village to work on interactive, safety-related activities.






Road safety

- Effectiveness of fluorescent/reflective r
- Speed and stopping distances, crossing
- Importance of cycle helmets.
- Implications of not wearing seatbelts.

Children of the 90s has a similar catchment area to Lifeskills

- Able to compare road safety behaviours and accidents in those who attended Lifeskills and those who did not.
- Lifeskills record attendance of schools, not individuals.
- National Pupil Database school registration details of CO90s participants used to:

➢ *Identify participants who attended school in Lifeskills catchment area when in Year 6 (between 2001-04)*

➢ *Link to Lifeskills attendance register*

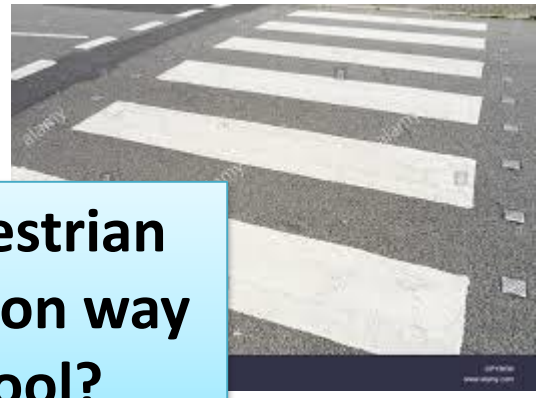
➢ ***60% of CO90s sample attended Lifeskills***

Outcomes reported by approx. 3000 CO90s participants at age 14 years

Own cycle helmet?

Cycle helmet use on last cycle?

Use pedestrian crossings on way to school?



Wore reflective or fluorescent clothing on last cycle?

Wore seatbelt last time in car?

Outcomes from linkage to hospital records for 1,768 CO90s participants

Hospital admission for reason relevant to Lifeskills, 11-16 years

A&E attendance for any reason, April '07 to 16 years

Those who attended more likely to use pedestrian crossings, but otherwise little difference in road safety measures...

Outcome	Attended Lifeskills	% yes for outcome
Uses pedestrian crossings [a]	**No**	**51.9**
	Yes	**59.2**
Owns cycle helmet [b]	No	60.7
	Yes	61.6
Wore cycle helmet [c]	No	35.8
	Yes	37.1
Wore hi-vis clothing [b]	No	3.4
	Yes	3.6
Wore seat belt last time in car	No	95.9
	Yes	96.7

Restricted to those who:

[a] cross 1+ road on way to school; [b] own a bike; [c] own bike and helmet.

Hospital admittance rare, but A&E attendance common

- **15** participants with linked hospital records had been admitted for a reason relevant to Lifeskills.

- **21% had attended A&E** at least once in the time period considered.

➢ ***20.1%*** *of those who attended Lifeskills*

➢ ***21.8%*** *of those who did not attend*

Focused cycle training

- In UK, national cycle proficiency scheme training (NCPS) began in 1947

- Rebranded ‘Bikeability’ in 2007

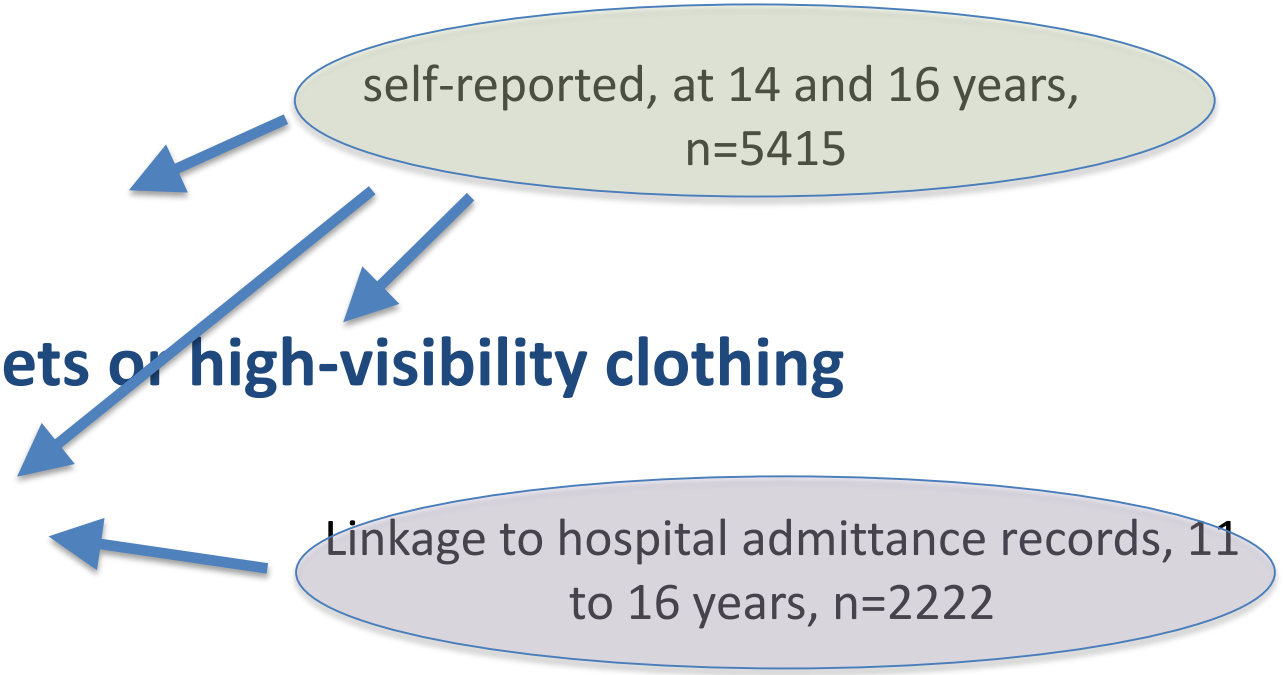
To ‘enable people to **cycle safely** and to **promote cycling** by improving skills, knowledge, attitudes, behaviour and hazard awareness’

• Use CO90s to determine if participation in cycle proficiency training associated with:

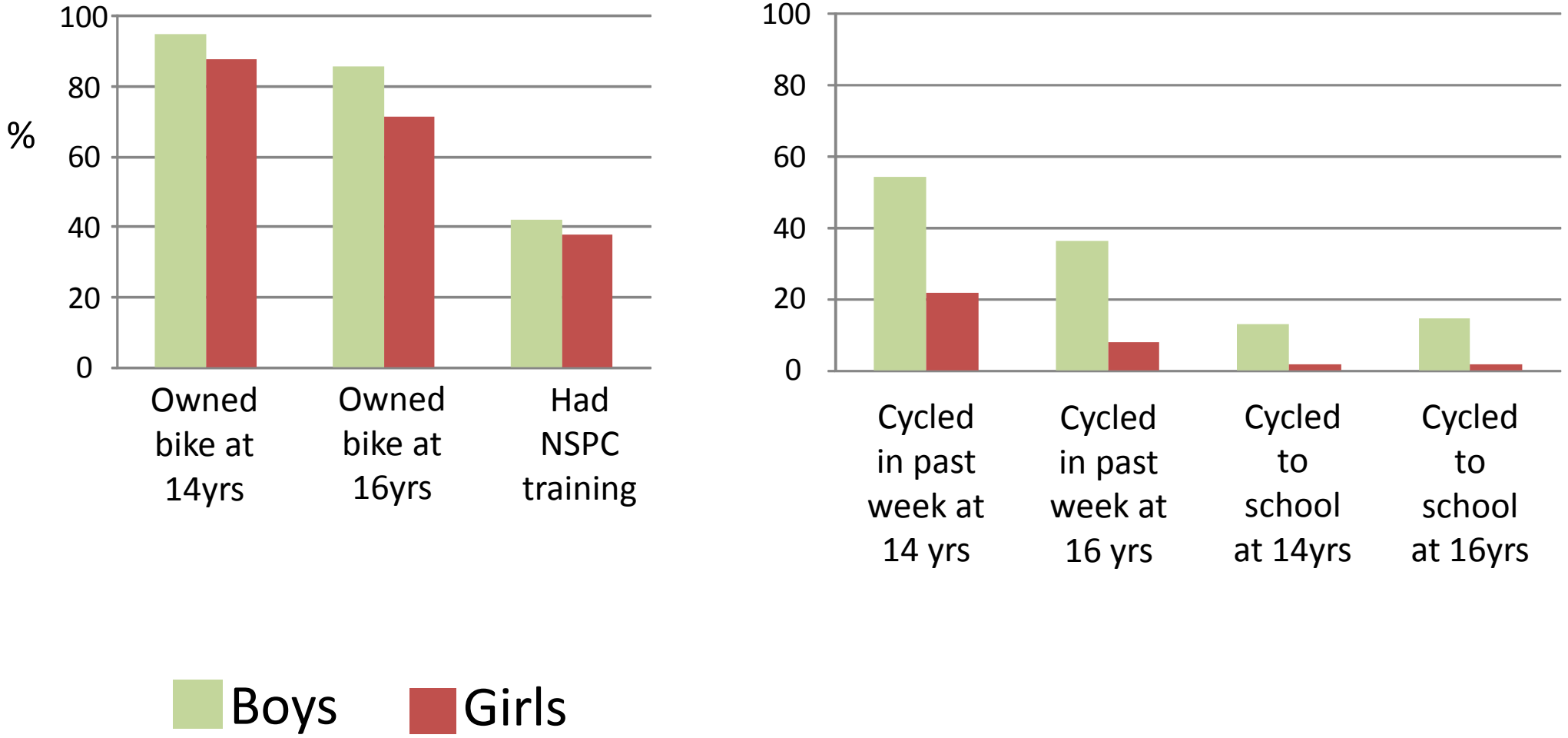
(1) cycling to school

(2) use of cycle helmets or high-visibility clothing

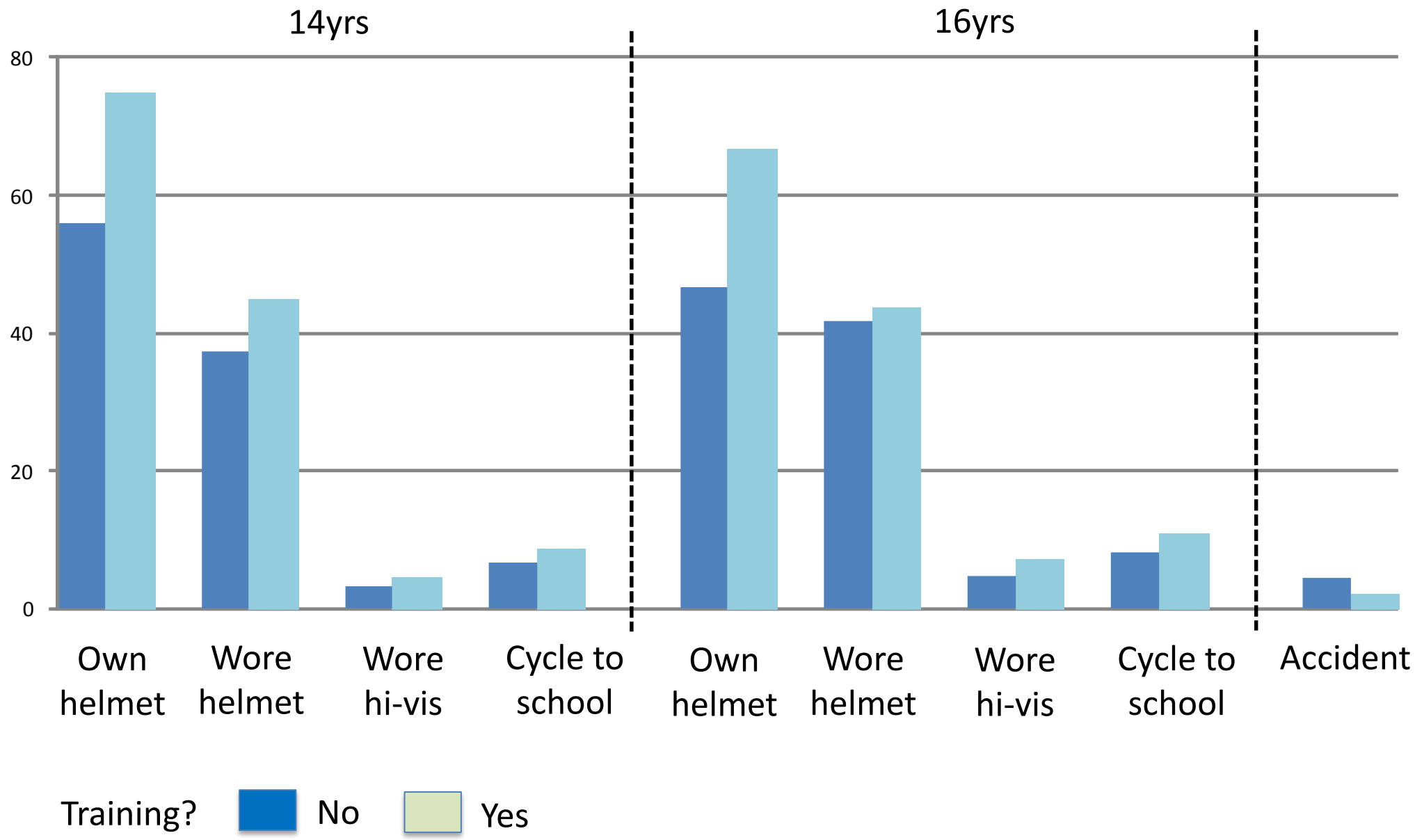
(3) cycle accidents



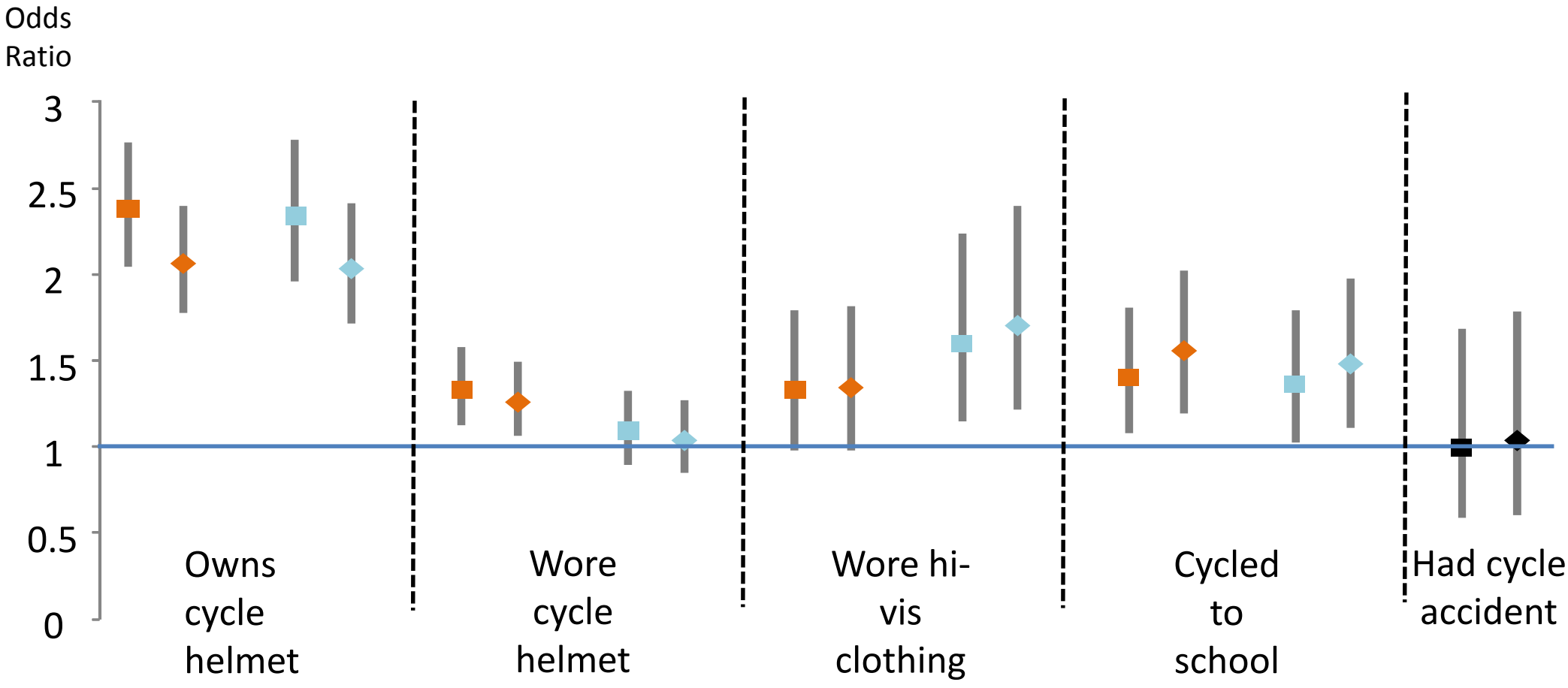
Bike ownership common, but less than half received NCPS training, and girls cycled less than boys



Outcomes by cycle training status...



Training associated with helmets, hi-vis clothing, and cycling to school...but not accidents



□ Adjusted for age and sex

◇ Also adjusted for measures of social class, maternal age, older siblings, resident father

14 years | 16 years | Either 14 or 16 years

Summary of key findings

- Lifeskills attendance associated with use of road crossings, but not other road-safety outcomes, or hospital attendance.

- Cycle training courses for children can have benefits that persist into adolescence (helmets, hi-vis, cycling to school).

- But irrespective of training -

➢ *Few cyclists wear a helmet, and very few hi-vis clothing*

➢ *Few girls cycle to school*

➢ *A&E attendance common*

➢ Results evidence a need for effective safety education, and potential to increase cycling, particularly in girls.

Main Limitations

- Risk of misclassification in exposure.
- None of the CO90s measures designed a priori to evaluate Lifeskills or Cycle Proficiency.
- Many objectives that we could not evaluate.
- Limited A&E linkage data availability.
- **Not an evaluation of how effective safety measures are at protecting children from injury.**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journal homepage: www.elsevier.com/locate/aap

An evaluation of the impact of 'Lifeskills' training on road safety, substance use and hospital attendance in adolescence

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Teyhan et al. BMC Public Health (2016) 16:469
DOI 10.1186/s12889-016-3138-2

BMC Public Health

RESEARCH ARTICLE Open Access

The impact of cycle proficiency training on cycle-related behaviours and accidents in adolescence: findings from ALSPAC, a UK longitudinal cohort

Alison Teyhan[1*], Rosie Cornish[1], Andy Boyd[1], Mary Sissons Joshi[2] and John Macleod[1]

The impact of cycle proficiency training on cycle-related behaviours and accidents in adolescence: findings from ALSPAC, a UK longitudinal cohort

University of BRISTOL
Avon Longitudinal Study of Parents and Children

A Teyhan[1*], R Cornish[1], A Boyd[1], M Sissons-Joshi[2], J Macleod[1]
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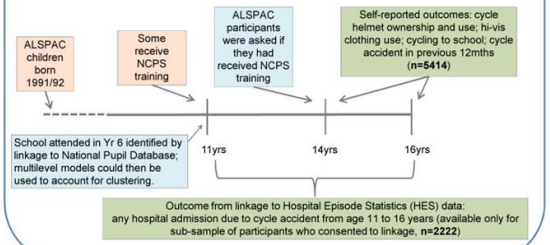
Key findings

- Trained children are more likely to cycle to school, to own a helmet, to have worn a helmet on their last cycle at 14yrs, and to have worn hi-vis clothing at 16yrs.
- Training not associated with self-reported involvement in cycle accident, and only 6 of our sample had hospital admission due to a cycle accident from 11-16yrs.
- Irrespective of training, use of hi-vis clothing very low, very few girls cycled to school, and less than half of helmet owners wore one on their last cycle.
- Findings indicate the further potential for interventions to encourage cycling, and safe cycling behaviours, in young people in the UK.
- However, education only one approach to making cycling safer: in countries with high levels of cycling, focus is often elsewhere e.g. separation of bikes and cars.

Using ALSPAC, a population-based cohort, to evaluate the NCPS

Aim: to determine if **National Cycle Proficiency Scheme (NCPS) training** is associated with cycling to school, helmet ownership, use of helmet or hi-vis clothing on last cycle, involvement in cycle accident, or admission to hospital due to a cycle injury, in adolescence.

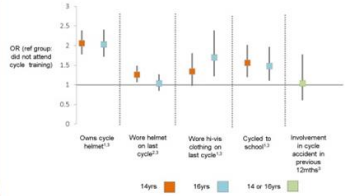


- **The majority of participants owned a bike.** Ownership higher at 14 than 16yrs, and higher in boys (14yrs: boys 95%, girls 88%; 16yrs: boys 86%, girls 71%).

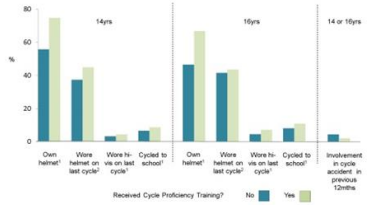
- **Girls cycled less than boys**. At 16yrs, 8% of girls had cycled in the previous week, compared to 37% of boys. One in 60 girls and 1 in 7 boys cycled to school.

- **40% had received NCPS training**. Trained children were more likely to be male, to be from higher socio-economic families, and less likely to have older siblings.

Training associated with helmets, hi-vis clothing, and cycling to school...but not accidents



But irrespective of training, few wore cycle helmet on last cycle, and very few wore hi-vis clothing or cycled to school



[1]Restricted to those who own a bike [2]Restricted to those who own bike and helmet [3]Models adjusted for child age and sex, family SEP, maternal and family characteristics, and clustering at the school level.

Background to cycle training for children in the UK

- The **National Cycle Proficiency Scheme (NCPS)** was introduced in 1958. Content and delivery varied by area (as the scheme was administered by local authorities), but it usually took place in the final year of primary school, consisted of 4-6 lessons in the school playground or on road, and finished with a cycling proficiency test.
- Scheme underwent changes and was rebranded 'Bikeability' in 2007. Overarching aim of the NCPS and Bikeability the same: 'to promote cycling and safe cycling behaviours'.
- Not all children receive training (currently ~50% of primary schools offer Bikeability), allowing outcomes to be compared between children who do and do not receive training.

www.bristol.ac.uk/alspac

A paper based on this work is available open access: BMC Public Health 2016,16:469

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