SICKLE CELL AND EDUCATION.

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Unit for the Social Study of
Thalassaemia
And
Sickle
Cell

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DE MONTFORT UNIVERSITY
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E·S·R·C
ECONOMIC
& SOCIAL
RESEARCH
COUNCIL

Research Team

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- Hackney PCT, Newham PCT, Birmingham PCT

The Research

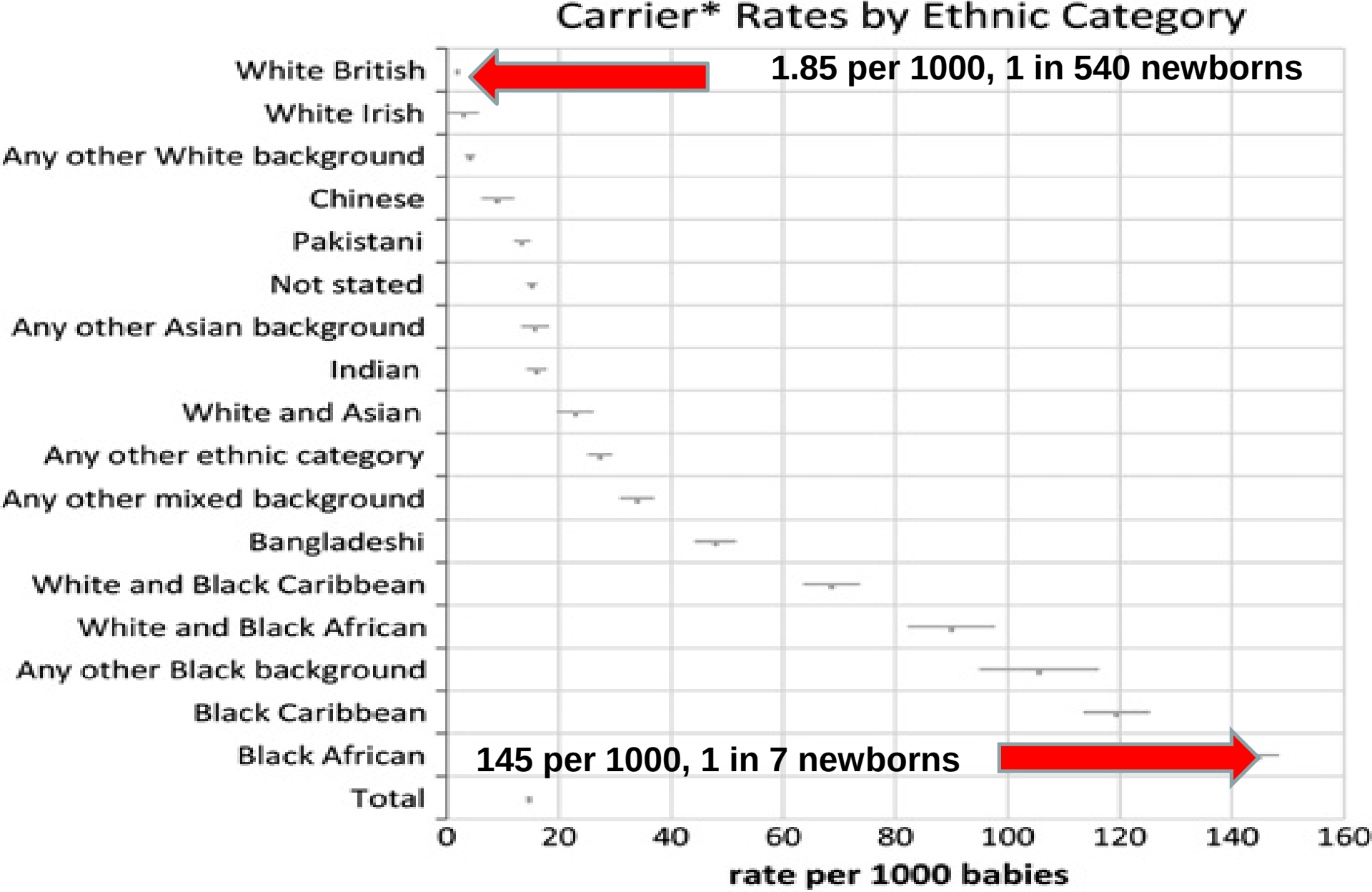
569 young people aged 4-25 about their educational experiences (questionnaire)

40 depth, tape-recorded interviews

Reported Type of Sickle Cell Disease	N	%
Sickle Cell Anaemia (HbSS)	411	72.2
Haemoglobin SC Disease (HbSC)	81	14.2
Not Known	56	9.8
Other (Sickle Beta + or -)	16	2.8
Missing	5	0.9
	569	100

Sample of 569 Young People with Sickle Cell Disease	
GENDER	
Female	288
Male	281
AGE	
4	16
5-10	243
11-18	276
19-25	32
Missing	2

Self-Reported Ethnicity	N=
Black Angolan	21
Black Caribbean	162
Black Congolese	19
Black Ghanaian	62
Black Nigerian	183
Black Sierra Leonean	46
Black Sudanese	6
Black Somali	6
Black Other	46
Asian	5
White English/Scottish/Welsh	3
Others White	3



* Carriers comprise the following results: FAS, FAC, FAD, FAE and other carriers

Source:Streetly, A., Latinovic, R., and Henthorn, J. (2010) Positive Screening and carrier results for the England-wide universal newborn sickle cell screening programme by ethnicity and area for 2005-7, *Journal of Clinical Pathology,* 63: 626-629

School Days Missed per Year (Sickle cell related absences only)

- Ranged from 0-200 days
- Average (Mean) 16.27 days (sd 25 days)
- Most frequently reported (Mode) 10 days
- 15 days: school required to make provision
- 63 sessions (half days) or 32 days = “persistent absence”
- Around 12% > 32 days

School Days Missed per Absence

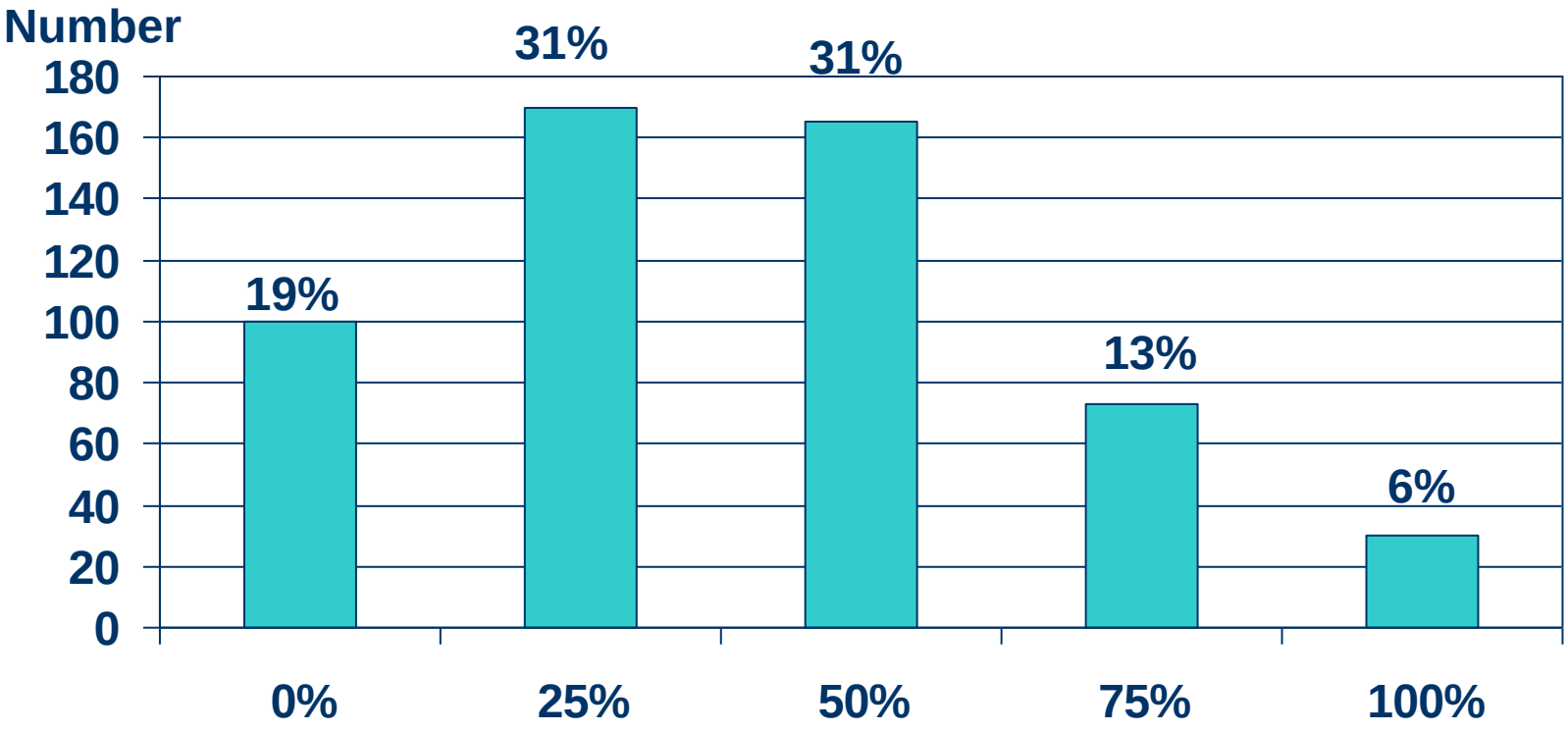
- 0-112 days
- Mean 7.14 days (sd 12 days)
- Most frequently reported (Mode) 2, 3 or 5 days

Clinical Symptoms and School Absences	Mean days absence	Probability
Reported HbSS Reported HbSC	17.4 13.9	n/s
Reported stroke No reported stroke	14.9 16.7	Unexpected direction
<u>Severity as indicated by service contacts</u>		
Reported regular blood transfusions Reported no regular blood transfusions	14.6 16.8	Unexpected direction
Reported emergency blood transfusion Reported emergency blood transfusion	17.4 15.6	n/s
Reported admitted to hospital 3x or more each year Reported not admitted hospital 3x or more each year	24.5 11.6	$p<0.000$
Reported taking hydroxyurea Not reported taking hydroxyurea	21.0 15.1	$p=0.048$
Only 14% of reported number of days off school explained by severity as indicated by four types of service contact of service contacts (Spearman rank correlation = 0.375)		
Only 4% of reported number of days off school explained by reported number of crises (Spearman rank = 0.211)		

School Absences

- Not easily explained by reported clinical symptoms.
- Look to social factors behind school experiences.

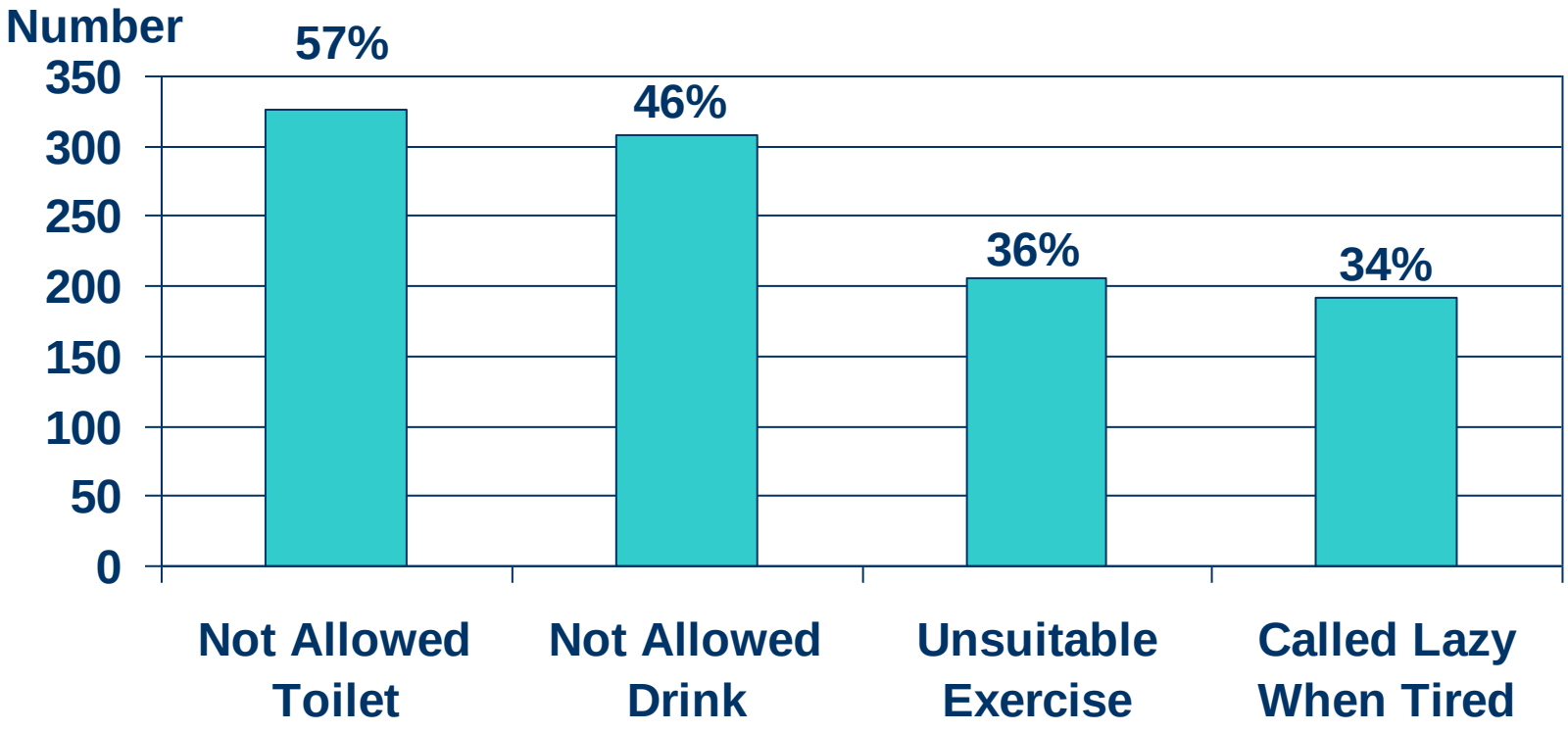
How Much Caught Up (%)?



How much helped to catch up (scale 0 to 100%)

[Mean = helped to catch up about 38%]

Reported Experiences in Schools



Water

- G8: [...] I had to get water when I was in class. I told my teacher but she said I should have got water from the nurse at lunchtime and, and also there’s a (warning score) it says you can’t go to get a drink during class time.

(Female, 13, Black African)

Toilet

- B2Mother: [...] there is also a second time when he went to school, my daughter went to pick him up, he was all wet in his pants. I was upset and said no, the teacher should know that this child has sickle cell, sometimes he needs help, he is a sick child, and of course he needs help. He wet his pants and stayed wet until my daughter picked him up.

(Male, 6 years old, Black Caribbean)

Toilet

- B4: [...] unless I would explain to them, just ask and nag them and then maybe. Cause they kept on saying, they kept on, they said it was like a way of preparing you for secondary school, cause [...] they thought we wasn’t allowed to go to toilet during class.

(Male, 16, Black African)

Temperature

- G7: [...] we weren’t allowed our coats on [...], and I was just, I remember that I started to cry cause I really wanted my coat, I am not going to freeze. Everyone else was cold, I wasn’t making a big an issue out of it, cause I remember everyone else around me was cold, even the people who came with us were like, yeah, it is a bit cold, these are young kids. And they was like no one more time around. And I stopped, I refused, I just could not be bothered, I just could not. I went mad, my fingers were just numb, everything was numb and I started to cry and I just felt a sharp pain, and then it all went downhill from then cause I had, my face was covered in gold paint and I started to cry and everything just kept running and I got sent home after that.

Temperature

- Interviewer: I was going to say how did the teachers react to?
- G7: It was, they were just like, ‘Oh it’s not that cold’. I remember one teacher, she didn’t like me very much, she was like ‘It’s not that cold, oh suck it up’. I was like, ‘I am not sucking it up, it’s cold, I want my coat’, [...] I got really numb and I got really still and then I just started to cry. I was in one spot crying real hard and I just felt this pain and a half.

(Female, 18, Black African)

Exercise

- B11: My teacher, I was in PE class and like he was keep on like, pushing me, pushing me, and I didn’t like much, football, and I’d tell him like I didn’t like doing and like when I was sitting out he’d come up to me ‘Stand up’ and like ‘Play the game’.

(Male, 15 years, Black Caribbean)

Lazy

- G1: [...] the teacher is ‘[Name], why is your arm on the table? Why are you so lazy?’ You know, it’s like I’m not lazy, I’m just tired. And it just got to a point where I was so tired I couldn’t be bothered to argue so I just walked out the class. And then the teacher came: ‘Why did you leave my class?’

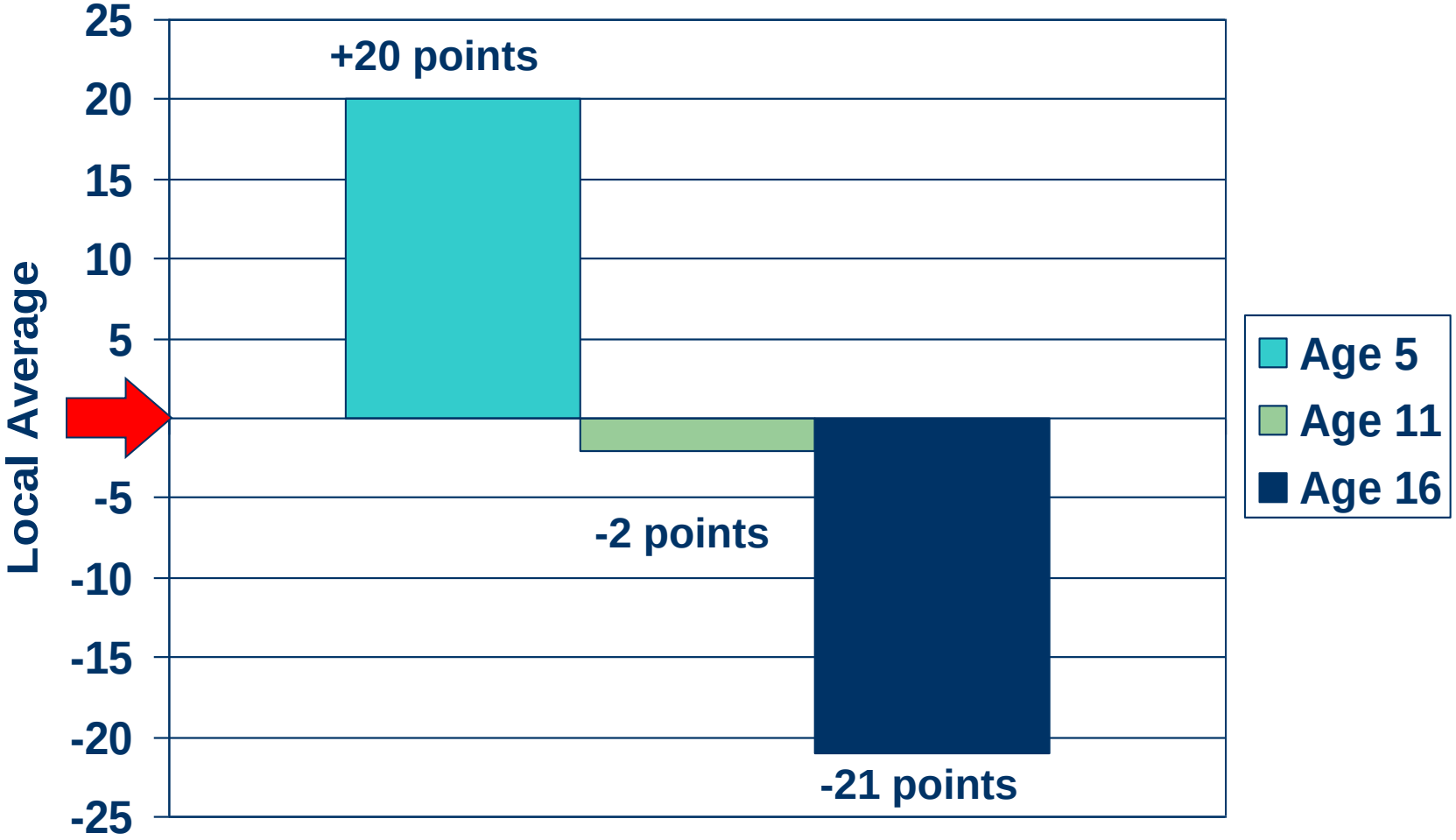
(Female, 16, Black African)

Pain

G6: Well, yeah, because it is really hard to take it in, even now I feel struggling with it. Like you try to listen, like you don't feel alert, and your body is aching, and it is just that you don't really learn, you cannot take it in, it is really hard. I mean it is hard in school, where school is, because of my attendance, they also put me in certain subjects, and what is it, I have like one, two, one three, like groups of, say when you do exams you can just get from C-E you cannot get higher than C.

(Female, 24 years, Black Caribbean)

Black Performance Relative to LEA Average



Source: Gillborn, D (2008) Racism and Education London: Routledge p100

Leg Ulcers

Late for class because walking slowly around large campus of school with leg ulcers

Parents

Mother seen as aggressive, pushy for advocating on behalf of her child with SCD

School questioned her psychology because a single parent

School took her more seriously when given research report documenting widespread mistreatment of children with SCD at school

Standard Advice

- “It is important to talk to your child's teachers and school nurse about sickle cell related problems your child may have in school”

  State of New Jersey, Department of Health and Senior Services

- “In schools, health promotion amongst both pupils and staff is important so that affected children are not bullied or stigmatised”

  Health Education Authority, United Kingdom

Range of teachers who reportedly “know” the person has SCD

- Head Teacher
- Head of School Year
- Class teachers
- PE teacher
- School Nurse
- Count of 0-5 range of people know

Range of negative experiences reported by the person has SCD

- Prevented drinking water
- Prevented using toilet
- Called lazy when tired
- Made to do unsuitable exercise
- Count of 0-4 of negative experiences reported

Adults Know v Negative Experiences

School adults who know	Number of Types of Negative Experience					
	0	1	2	3	4	Total
0	24	19	5	5	6	59
1	12	19	13	18	8	70
2	22	19				70
3	20	27		?		126
4	22	15				91
5	34	23				110
	134	117	143	119	56	569

Adults Know v Negative Experiences

School adults who know	Number of Types of Negative Experience					
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0	24	19	5	5	6	59
1	12	19	13	18	8	70
2	22	19	13	18	8	70
3	20	27	42	28	9	126
4	22	15	23	22	9	91
5	34	23	17	19	17	110
	134	117	143	119	56	569

Conclusion:
Change the Social Environment

- Mixed response to others knowing they have sickle cell disease
- Find way to support young people with SCD irrespective of whether they themselves are open about their SCD
- “Care in community” care not in hospital is not just care at home, but care at school
- Economic costs of unnecessary illness caused by school environment

Research Web-Site

http://www.sicklecelleducation.com

Downloadable 4 page research summary

Links to six academic articles

Model School Policy Leaflet

BY SA

Thank You!

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