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Navigating uncertain illness trajectories for young children with serious infectious illness: a modified grounded theory study.

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1 **Supporting Information File 1 (S1 Fig)**

2 **Navigating uncertain illness trajectories for young children with serious infectious illness:**

3 **Documentary analysis report.**

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15 **Key messages from documentary analysis of existing evidence**

16 - Higher deprivation in the city at the centre of Study Area 1 (Study Area 1 City) and in one
17 town (2) in the north of Study Area 2 than in other parts of the study areas.

18 - Higher children’s mortality rate and higher low birth weight full term in Study Area 1 City
19 than other study areas and above the national average for England.

20 - Variable pattern of health service provision

21 - Higher emergency department attendance by 0-4 year olds in Study Area 1 as a whole
22 (excluding the city) than Study Area 2 and above the England average.

23 - The youngest children use the most hospital health care, declining year on year.



- 24 - Hospital use is higher in the winter months.
- 25 - Lack of access to child death review (CDR) data limiting ability for lessons to be learnt for the
- 26 future. This also means we are unable to look for the persistence of any modifiable factors in
- 27 our data.

28 Overview.

29 The primary aim of the documentary analysis was to map identified modifiable organizational,

30 environmental and human factors in reports concerned with child deaths in each of the study areas,

31 compare these data between sites in the context of patterns of service use (from Hospital Episode

32 Statistics (HES) data and ambulance service data) and the services available to children, to identify

33 patterns which can then be explored in the data collection stages of the project. The data has been

34 presented to reflect the two study areas and to contextualise the two hospitals from which the families

35 were recruited for the first data collection stage of the study. Within this report Study Area 1 refers to

36 a county with a city at the centre, and Study Area 2 refers to the eastern half of an adjacent county,

37 containing four districts (three towns and a more rural district), served by the district general hospital

38 which formed the second recruitment site.

39 General population data.

40 *Table 1 General population data for study areas including inequality factor and wider determinants*

41 *of health factor*

	Study Area 1		Study Area 2				England
Population Health Profile 2018/2019	City	Rest of county	Town 1	Town 2	Rural area	Town 3	
Population Number of Persons	355,218	698,268	101,266	70,827	93,906	79,478	55,977,178
Children aged 0-4 (%)	7	5.3	6.1	7.2	5.4	6.3	6
Ethnic minorities (%)	48.6	7.8	5.1	7.9	2.8	6.9	13.6
Inequalities							
Deprivation Score	30.9	12.3	19.2	25.7	13.9	21.7	21.8
Wider determinants of health							
Children < 16 in low-income families (%)	23	10.9	14.2	17.3	11.2	16.4	17
People in employment (%)	66.2	79.8	73.4	77.3	82.6	73.5	75.6



42 Source: Local Authority Health Profiles 2019 Published 03/03/2020 (1)

43

44 The above table shows that in relation to inequality and the wider determinants of health the study
45 areas are generally the same as or better than the national rates. This is with the exception of Study
46 Area 1 City which has a higher percentage of ethnic minorities and of children that are in low income
47 families, and a lower percentage of people in employment than England and the overall rates for Study
48 Area 1 and the four Study Area 2 districts.

49

50 [Child population and child health data](#)

51 Table 2 below shows live births, still births and still birth rates (SBR) for both study areas in 2018. The
52 way the data is reported is along authority boundaries, therefore, the geographical area is reported
53 for the City in Study Areas 1 which is a unitary authority and for the rest of the county. Study Area 2 is
54 constituted from four districts. The figures below show Town 2 within Study Areas 2 as having the
55 highest still birth rate, higher than the rate for England as a whole. Also, the Rest of county for Study
56 Areas 1 as having the lowest still birth rate, lower than the England rate overall.

57 *Table 2 Child population data*

ONS 2018	Study Area 1		Study Area 2				England
	City	Rest of county	Town 1	Town 2	Rural area	Town 3	
Live Births	4,611	6,875	1,191	888	910	891	625,651
Still births	20	18	5	5	2	2	2,520
Still birth rate per 1,000	4.3	2.6	4.2	5.6	-	-	4.0

58 Source: Births in England and Wales: summary tables (2)

59 In Table 3 below, Study Area 1 City has the highest percentage of low birth weight full term babies and
60 is higher than the England average. This city also has a higher infant mortality rate than the county in
61 which it sits and Study Area 2 and is above the national average. Study Area 1 County has the highest
62 0 – 4 years A & E attendances, above the City and Study Area 2, and higher than the England average.
63 Study Area 2 has lower attendance rates than the England average.

64



65 *Table 3 Child health data*

Child Health Profile	Study Area 1		Study Area 2	England
	City	Rest of county		
Infant mortality (per 1,000 live births) 2016/18	5.9	3.5	4.2	3.9
Child mortality rates (1-17yrs) (per 100,000 of 1-17 population)	16.4	9.7	9.6	11.0
MMR vaccination (2 year olds) 2017/18	91.5%	95.8%	91.3%	90.3%
DTaP vaccine (2 year olds) 2017/18	94.9%	97.6%	95.3%	94.2%
Low birth weight of term babies 2018	4.45%	2.50%	2.29%	2.86%
A&E attendances 0-4yrs per 1,000 0-4 population	643.9	758.5	605.7	655.3

66 Source: Child and Maternal Health profiles (3)

67 [Child Death Reviews](#)

68 Access to child death review data was difficult and limited data was obtained. Child Death Review
 69 information regarding children who had died from infection during the two years 2015-2017 was
 70 obtained from Study Area 2 county (not including the City). This data was very limited giving figures
 71 for number of children within the study criteria, their age, gender, the first three letters of their post
 72 code, the year they died and where they died. No further information was available, such as any
 73 learning from these events. No information was obtained from Study Area 1 City or Study area 2. The
 74 reason given to some degree related to concerns about confidentiality, however the main reported
 75 reason for difficulties with sharing data was capacity within the department to have the time
 76 necessary for sharing the information. This was the main reason that Study Area 2 reported for being
 77 unable to send through the information to the research team. The data we received from Study Area
 78 1 county met the criteria of our study, children over 28 days and under five years old, who had had an
 79 infectious illness. From the data that was received for this county five children died, four of the
 80 children were under 1 year old, the fourth was 2 years 1 month. Of these children, four were male and
 81 one female. Three children died in the emergency department and two died in the paediatric intensive
 82 care unit. When looking at the residential postcode for these children, three lived close to the centre



83 of the city, one lived on the edge of the city and one lived around a town in the north of Study Area 1.
84 It is useful to note that the children's emergency department is in the centre of Study Area 1 City. It is
85 not possible to ascertain where the child became unwell but at least three of these children had family
86 homes close to the children's emergency department. There was no information regarding the nature
87 of the infectious illness, for example bronchiolitis, meningitis, and therefore difficult to compare with
88 the presentations of illness within the recruited families. These are very small numbers but when
89 compared to recruitment information for Study Area 1, none of the recruited families had children
90 who died as a result of their illness.

91 The difficulties with obtaining data and how little data was available highlights the lack of information
92 available regarding modifiable factors or learning from events and reviews.

93 [First contact urgent care services available in study areas](#)

94 The pattern of urgent care services available to families varied significantly in the two study areas.
95 Study Area 1 had a children's emergency department within a large teaching hospital and six urgent
96 care centres most of which were situated in the county surrounding the city. Study Area 2 had a
97 small children's emergency area in a general emergency department of the district general hospital
98 and one urgent care centre in Town 2.

99 [Ambulance service use data](#)

100 The total number of incidents relating to children meeting the study criteria for the two years
101 2015/16 and 2016/17 is 632 incidents. Table 4 shows the numbers per year in each study area. This
102 does not include calls to the service for children where the report stated a non-infection related
103 reason, such as a fall or an injury.

104 *Table 4 Ambulance service response to calls by year and area*

105			
Numbers by area			
		Study Area 1	Study Area 2
2015/16	N = 440	207	98
2016/17	N = 192	172	6



108 There is a considerable difference in activity between the two years, 440 incidents 2015/16 and 192
109 16/17, a drop of 56%. This is in both study areas, but most significantly in Study Area 2, which has a
110 91% drop in incidents. Table 5 shows those conveyed to hospital.

111 *Table 5 Children conveyed to hospital by year and area*

	Conveyed to hospitals		
	Total conveyed	Study Area 1	Study area 2
2015/16	376	161	95
2016/17	160	144	4

114

115 [Hospital Episode Statistics data](#)

116 Hospital Episode Statistics is a way of counting activity within a hospital. It is based on diagnostic
117 classifications and records an episode of continuous care. A child may have several episodes of care
118 during their stay in hospital and stays in hospital will not always be represented by a single HES record
119 (4). The numbers in Tables 6, 7 and 8 refer to hospital episodes, and not numbers of children.
120 Therefore, it does not give the number of children receiving treatment, but it does show the level of
121 activity and busyness of the hospital. The Teaching Hospital (TH) in Study Area 1 had approximately
122 33% more activity than the District General Hospital (DGH) in Study Area 2 during 2015/16, and
123 approximately 44% more activity than the DGH in 2016/17.

124 Overall November has the most HES activity for these two years (1,311 episodes), then December (836
125 episodes) followed by January (605 episodes), October (533 episodes) and February (211 episodes) -
126 see Table 6. This information was used to plan the recruitment and data collection.

127

128



129 *Table 6 Hospital Episode Statistics by year and month*

Hospital Episode Data. Children aged 28 days – 4 years													
	Apr	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Totals
2015/16													
TH	242	245	179	180	166	243	253	384	370	305	271	252	3,090
DGH	154	119	126	149	105	127	205	250	233	195	211	192	2,066
2016/17													
TH	227	261	262	245	177	290	319	387	298	300	228	273	3,267
DGH	136	172	158	185	131	149	214	289	233	190	193	205	2,255

130

131 Table 7 shows the number of episodes of care by age group and it was the youngest children who used
 132 the most hospital health care, declining year on year.

133 *Table 7 Hospital Episode Statistics for TH and DGH by age and year*

TH HES activity by age						
Age in years	0	1	2	3	4	Total
2015/16	1049	823	520	405	293	3,090
2016/17	1099	892	523	425	328	3,267
DGH HES activity by age						
Age in years	0	1	2	3	4	Total
2015/16	763	547	300	250	206	2,066
2016/17	854	583	330	285	203	2,255

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