Multicentre service evaluation of presentation of newly diagnosed cancers and type 1 diabetes in children in the UK during the COVID-19 pandemic

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ABSTRACT

Background The COVID-19 pandemic led to changes in patterns of presentation to emergency departments. Child health professionals were concerned that this could contribute to the delayed diagnosis of life-threatening conditions, including childhood cancer (CC) and type 1 diabetes (T1DM). Our multicentre, UK-based service evaluation assessed diagnostic intervals and disease severity for these conditions.

Methods We collected presentation route, timing and disease severity for children with newly diagnosed CC in three principal treatment centres and T1DM in four centres between 1 January and 31 July 2020 and the corresponding period in 2019. Total diagnostic interval (TDI), patient interval (PI), system interval (SI) and disease severity across different time periods were compared.

Results For CCs and T1DM, the route to diagnosis and severity of illness at presentation were unchanged across all time periods. Diagnostic intervals for CCs during lockdown were comparable to that in 2019 (TDI 4.6, PI 1.1 and SI 2.1 weeks), except for an increased PI in January–March 2020 (median 2.7 weeks). Diagnostic intervals for T1DM during lockdown were similar to that in 2019 (TDI 16 vs 15 and PI 14 vs 14 days), except for an increased PI in January–March 2020 (median 21 days).

Conclusions There is no evidence of diagnostic delay or increased illness severity for CC or T1DM, during the first phase of the pandemic across the participating centres. This provides reassuring data for children and families with these life-changing conditions.

INTRODUCTION

The UK instigated a national lockdown on 23 March 2020 in response to the evolving COVID-19 pandemic. There was an order to stay at home with permission to leave for essential purposes only. These rules were in place in England until the 1 June 2020 and Scotland until the 29 May 2020, when people were permitted to meet outside with up to six and eight people, respectively.1 However, in general, the lockdown restrictions in the early stages of the pandemic in the UK were very similar across all countries. Specific individuals with conditions that put them at high risk of serious illness from COVID-19 were instructed to `shield' by remaining at home and avoiding all face-to-face contact.2

The UK public health response to the COVID-19 pandemic led to major changes in service utilisation of emergency departments (ED), with an observed 49% reduction in attendances in the week following the March 2020 announcement of lockdown.3 More specifically, this reduction was also seen in children’s ED attendances in both Scotland and Italy.4,5 This raised concern among
child health professionals that the pandemic could be
associated with delayed presentation of children with
significant illnesses including life-changing childhood
conditions such as type 1 diabetes (T1DM) and child-
hood cancer (CC). We were concerned there may have
been an increase in delays in seeking medical advice (the
patient interval (PI)) and/or accessing initial investiga-
tions and interventions (the system interval (SI)), leading
to a prolongation of the total diagnostic interval (TDI).7

In the UK, 1900 children are diagnosed with cancer
each year.89 The diverse and often insidious nature of
presenting symptoms combined with the low incidence
and lack of awareness of childhood malignancy may
contribute to a prolongation of the TDI. Recent adult
studies report that referrals via the urgent 2-week
wait pathway for suspected cancer diagnoses decreased
by 84% from March to May 202011 and 60% in June 2020.10
One study predicted a reduction of over 10% in 10-year
survival of adults with cancer,11 while another predicted
an excess of 1307 cancer deaths.10 The evidence is equiv-
cal as to whether delays in time to diagnosis is associated
with survival from CCs,11–13 however the psychological
and economic distress on families awaiting a CC diag-
nosis should not be underestimated.12

Experience of the COVID-19 pandemic for children
with T1DM has been inconsistent. A survey of 53 Italian
paediatric diabetes centres found that the number of chil-
dren with a new diagnosis of diabetes from February to
April 2020 was 23% lower than the corresponding period
in 2019. The survey also found the proportion of patients
presenting with severe diabetic ketoacidosis (DKA) was
increased.14 A 30-patient UK study reported an apparent
increase in new-onset T1DM during the first 6 weeks of
lockdown.15

The aim of the project was to assess any association of
the COVID-19 pandemic on new diagnoses of CC and
T1DM at participating UK centres.

METHODS

Study design

We undertook a multicentre service evaluation using
existing clinical case data assessing the route of diagnosis,
diagnostic interval and severity of presentation.

Eligibility criteria were:
1. All children who attended three centres (the Royal
Hospital for Sick Children (RHSC), Edinburgh,
Leeds Teaching Hospitals NHS Trust and Nottingham
University Hospitals (NUH) NHS Trust) and were di-
gnosed with cancer between 1 January and 30 June
2019 and the corresponding period in 2020.
2. All children who attended four centres (the RHSC,
Edinburgh, NUH NHS Trust, University Hospital
Wishaw and Ninewells Hospital, Dundee) and were
diagnosed with T1DM between 1 January and 31 July
2019 and the corresponding period in 2020.

All centres were the central referral centres for chil-
dren within their region who received a new diagnosis of
cancer or of T1DM.

A standard proforma (online supplemental files 1 and
2) was used to retrospectively collect information on
demographics, diagnosis, referral pathway and clinical
presentation. We also collected information on whether
patients were shielding at presentation (following
specific government guidelines to minimise risk of SARS-
CoV-2 exposure for those considered clinically extremely
vulnerable). Dates of symptom onset, first presentation
to healthcare and final diagnosis were used to calculate
TDI (time between symptom onset to diagnosis), PI
(time between symptom onset to first presentation) and
SI (time between first presentation to diagnosis).2 Data
were collected and entered into a centralised database by
named individuals at the participating centres. Data were
double checked at the point of entry to the database and
then reviewed by the database administrator. Any discrep-
ancies or queries from the database administrator were
then highlighted and re-reviewed by the data collectors
at each centre.

Statistical analysis

Descriptive analyses, χ² test and Mann-Whitney U or
Kruskal-Wallis tests were used to describe patterns of
referral and illness, comparing the differences of key
measures among different time periods (1 January–31
March 2020 and 1 April–31 July 2020 and the corre-
ponding period in 2019). Pairwise comparisons of propor-
tions were carried out using the Z test with Bonferroni
corrections. All analyses were performed with IBM
SPSS V.26.0 for Windows (IBM Corp. Armonk, New York,
USA) and p<0.05 was considered statistically significant.

RESULTS

Study population

Childhood cancer

There were 253 new diagnoses of CC during the study
period (table 1). Of these, 164 (64%) were male and
55 (22%) were from a black, Asian and minority ethnic
(BAME) background. Patients were diagnosed at one
of three principal treatment centres (Edinburgh=64,
Leeds=100, Nottingham=89). There were no signifi-
cant differences in the distribution of gender, ethnic
background or age at diagnosis between study periods
(table 1). The proportion of tumour type in each eval-
uation period did not change. Overall, 95% (53/56) of
patients who presented during the lockdown period were
not shielding.

Overall, there was a 17% reduction in number of inci-
dent CC cases between 2019 (n=138) and 2020 (n=115).
This change varied between centres (4% increase to 40%
reduction) (figure 1).

Type 1 diabetes

There were 187 new diagnoses of T1DM during the study
period (table 2). Of these, 90 (48%) were male and
18 (10%) were from a BAME background. Patients were
diagnosed at one of the four participating centres (Edinburgh=45,
There were no significant differences in gender, ethnic background or age at diagnosis between the study periods (table 2). Overall, 91% (42/46) of those who presented during the lockdown period were not shielding.

A reduction in the numbers of new cases of T1DM between the months of April and July 2020 and the identical period in 2019 occurred in three of the four units. Overall, there was a 3%–24% reduction in new diagnoses of T1DM between the months of January and July 2020 compared with the corresponding period in 2019 in all centres (figure 1).

**Route to diagnosis**

**Childhood cancer**

Across all time points, 60% of children (152/253) were diagnosed within three or fewer healthcare contacts, 25% within four to six contacts, 8% within seven to nine contacts and 6% required more than 10 contacts prior to diagnosis. There was no significant difference in distribution across three time periods (p=0.569) or January–March 2020 and April–June 2020 (p=0.359) (online supplemental figure S1a). General practice was the first point of healthcare contact in about half of the patients across all time periods (54% in 2019, 49% in January–March 2020, 48% in April–June 2020) (online supplemental figure S1b). Overall, 63% of patients presented to hospital as an emergency presentation either from primary care or to the ED. Overall, 36% of children had their diagnostic investigation requested as an inpatient. These proportions were consistent across all three time periods (p=0.405) (online supplemental figure S1c).

### Table 1 Summary of incident childhood cancer patient characteristics (n=253)

<table>
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<th></th>
<th>Total (n=253)</th>
<th>January–June 2019 (n=138)</th>
<th>January–March 2020 (n=59)</th>
<th>April–June 2020 (n=56)</th>
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<tr>
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<td>Col%</td>
<td>n</td>
<td>Col%</td>
<td>n</td>
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<td><strong>Gender</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>81</td>
<td>59%</td>
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<td>91</td>
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<td>57</td>
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<td>99</td>
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<td>53</td>
<td>38%</td>
<td>25</td>
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<tr>
<td>5–11</td>
<td>92</td>
<td>37%</td>
<td>52</td>
<td>38%</td>
<td>19</td>
</tr>
<tr>
<td>12+</td>
<td>61</td>
<td>24%</td>
<td>33</td>
<td>24%</td>
<td>14</td>
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<td>78%</td>
<td>107</td>
<td>78%</td>
<td>47</td>
</tr>
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<td>22%</td>
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<td>22%</td>
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<tr>
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<td>99%</td>
<td>138</td>
<td>100%</td>
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<td>69</td>
<td>27%</td>
<td>33</td>
<td>24%</td>
<td>17</td>
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<tr>
<td>CNS tumour</td>
<td>74</td>
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<td>48</td>
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<tr>
<td>All other tumour types</td>
<td>110</td>
<td>43%</td>
<td>57</td>
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<td><strong>ICU stay</strong></td>
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<td></td>
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<td>223</td>
<td>88%</td>
<td>120</td>
<td>87%</td>
<td>55</td>
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<td>26</td>
<td>10%</td>
<td>17</td>
<td>12%</td>
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<td>4</td>
<td>2%</td>
<td>1</td>
<td>1%</td>
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<td>21</td>
<td>8%</td>
<td>11</td>
<td>8%</td>
<td>3</td>
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<tr>
<td>10 or more</td>
<td>16</td>
<td>6%</td>
<td>7</td>
<td>5%</td>
<td>4</td>
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</table>

BAME, black, Asian and minority ethnic; CNS, Central Nervous System; Col%, Column Percentage; HCP, Healthcare Professionals; ICU, Intensive Care Unit.
Figure 1  Number of newly diagnosed of childhood cancer and type 1 diabetes (T1DM) cases between January and July 2020 compared with the corresponding period in 2019. (A, C) Data covers all participating centres contributing data to the project by month. Shaded areas indicate national lockdown months. (B, D) Data by individual centre over the periods January–June/July in 2019 and 2020.
Type 1 diabetes

The source of referral leading to diagnosis was the ED in 30% (14/46) of cases between April and July 2020. This compared with 12% (5/43) of cases diagnosed between January and March 2020 (p=0.091) and 19% (19/98) of cases diagnosed over the period of January–July 2019 (p=0.426). Overall, 63% of patients had been referred by their General Practitioner (GP) between April and July 2020, compared with 81% of patients in the preceding 3 months, and 72% of patients in 2019 (online supplemental figure S2).

Time to diagnosis

Childhood cancer

Across all three centres, there was no significant difference in the distribution of TDI between 2019 (median 4.5, IQR 2.3–10.9 weeks) and January–March 2020 (median 5.6, IQR 3.4–15.3 weeks) or April–June 2020 (median 4.6, IQR 2.7–11.9 weeks) (p=0.351) (figure 2 and online supplemental figure S3a). There was a significant increase in PI between 2019 and January–March 2020 (median 0.9, IQR 0.1–2.1 vs median 2.7, IQR 0.7–4.4 weeks, p=0.005), but during April–June 2020 there was no significant difference compared with 2019 (median 1.1, IQR 0.3–4.7 vs median 0.9, IQR 0.1–2.1 weeks, p=0.383) (figure 2). SI was stable across all time points (figure 2). The pattern remained the same when the 2019 data were further split into January–March and April–June (online supplemental figure S5). Differences in PI across four time periods was significant (p=0.011) and pairwise comparisons showed that PI in January–March 2020 was significantly higher than that in the January–March 2019 (median 2.7, IQR 0.7–4.4 vs median 0.6, IQR 2.0 weeks, p=0.008).

Table 2 Summary of incident T1DM patient characteristics (n=187)

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<tr>
<th></th>
<th>Total (n=187)</th>
<th>January–July 2019 (n=98)</th>
<th>January–March 2020 (n=43)</th>
<th>April–July 2020 (n=46)</th>
<th>p value</th>
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<td><strong>Gender</strong></td>
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<td></td>
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</tr>
<tr>
<td>Male</td>
<td>90 (48%)</td>
<td>46 (47%)</td>
<td>23 (53%)</td>
<td>21 (46%)</td>
<td>0.718</td>
</tr>
<tr>
<td>Female</td>
<td>97 (52%)</td>
<td>52 (53%)</td>
<td>20 (47%)</td>
<td>25 (54%)</td>
<td></td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
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</tr>
<tr>
<td>Under 5</td>
<td>32 (17%)</td>
<td>22 (22%)</td>
<td>5 (12%)</td>
<td>5 (11%)</td>
<td></td>
</tr>
<tr>
<td>5–11</td>
<td>87 (47%)</td>
<td>43 (44%)</td>
<td>18 (42%)</td>
<td>26 (57%)</td>
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<tr>
<td>12+</td>
<td>68 (36%)</td>
<td>33 (34%)</td>
<td>20 (47%)</td>
<td>15 (33%)</td>
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<tr>
<td><strong>BAME background</strong></td>
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<tr>
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<td>168 (90%)</td>
<td>87 (89%)</td>
<td>41 (95%)</td>
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<td></td>
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<tr>
<td>Yes</td>
<td>18 (10%)</td>
<td>11 (11%)</td>
<td>2 (5%)</td>
<td>5 (11%)</td>
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<td>183 (98%)</td>
<td>98 (100%)</td>
<td>43 (100%)</td>
<td>42 (91%)</td>
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<td>Yes—self-isolation</td>
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<td>0 (0%)</td>
<td>3 (7%)</td>
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<tr>
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<tr>
<td><strong>Diabetic ketoacidosis</strong></td>
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<td>No</td>
<td>112 (60%)</td>
<td>59 (61%)</td>
<td>26 (60%)</td>
<td>27 (59%)</td>
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<tr>
<td>Mild/Moderate</td>
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<td>25 (26%)</td>
<td>12 (28%)</td>
<td>9 (20%)</td>
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<tr>
<td>Severe</td>
<td>28 (15%)</td>
<td>13 (13%)</td>
<td>5 (12%)</td>
<td>10 (22%)</td>
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<td>94 (96%)</td>
<td>43 (100%)</td>
<td>45 (98%)</td>
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<td>4 (4%)</td>
<td>0 (0%)</td>
<td>1 (2%)</td>
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<tr>
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<td>169 (91%)</td>
<td>90 (92%)</td>
<td>39 (93%)</td>
<td>40 (87%)</td>
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</tr>
<tr>
<td>Yes</td>
<td>17 (9%)</td>
<td>8 (8%)</td>
<td>3 (7%)</td>
<td>6 (13%)</td>
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<td>164 (92%)</td>
<td>87 (92%)</td>
<td>37 (95%)</td>
<td>40 (89%)</td>
<td></td>
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<td>&gt;1</td>
<td>15 (8%)</td>
<td>8 (8%)</td>
<td>2 (5%)</td>
<td>5 (11%)</td>
<td></td>
</tr>
</tbody>
</table>

BAME, black, Asian and minority ethnic; Col%, Column Percentage; HCP, Healthcare Professionals; ICU, Intensive Care Unit; T1DM, type 1 diabetes.
There was no significant difference in TDI across all time periods for leukaemias, CNS tumours and solid tumours in subgroup analyses (figure 3). There was no significant difference in PI or SI for individual principal treatment centres or tumour types (figure 3 and online supplemental figure S3b,c).

Type 1 diabetes
Median TDIs for incident T1DM cases were 16 (IQR 8–28), 21 (IQR 14–32) and 15 (7–22) days for 2019, January–March 2020 and April–July 2020, respectively. There was no significant difference across the three time periods (p=0.119). A similar pattern was observed in PI. The comparison across all time periods was not significant (p=0.054), subanalyses showed that PI was longer during January–March 2020 compared with April–July 2020 (median 21, IQR 14–32 vs median 14, IQR 7–22 days, p=0.025) and 2019 (median 14, IQR 7–28 days, p=0.036) (figure 4 and online supplemental figure S4).

When the 2019 data were further split into January–March and April–June, differences in PI across four time periods became significant (p=0.041) and none of the post hoc pairwise comparisons reached significant level (online supplemental figure S6).

Severity of presentation
Childhood cancer
Within 7 days of diagnosis, 10% (26/253) of patients with CC required admission to paediatric intensive care. This was stable across all time periods (p=0.275) (table 1).

Type 1 diabetes
The proportion of patients presenting in DKA was 41% (19/46) in the period April–July 2020, 40% (17/43) for the time period January–March 2020 and 39% (38/98) for the time between January and July 2019. There was no significant difference in the proportion of patients in DKA across all time periods. The proportion of children presenting with severe DKA (pH <7.1, serum bicarbonate <5 mmol/L) showed no statistical difference between lockdown April–July 2020 (22%, 10/46) compared with 12% (5/43) January–March 2020 and 13% (15/98) January–July 2019 in the periods prior to lockdown (p=0.447). There was no significant difference in the rate of intensive care admission or requirement for ventilatory support (table 2).

DISCUSSION
We have demonstrated that the first phase of the COVID-19 pandemic was not associated with route of presentation, TDI or disease severity at presentation for children with a new diagnosis of CC or T1DM at the study centres. Given the reported reduction in paediatric ED attendance, it had been predicted that both the PI and TDI would be prolonged and clinical presentations would be more severe. This prediction was not supported by our study.

A snapshot survey was commissioned in April 2020 by the Child Cancer Smart Team in conjunction with the Childhood Cancer and Leukaemia Group (CCLG) to obtain the absolute numbers of new diagnoses of CC at each principal treatment centre in the UK (online supplemental file 3). This survey revealed 27% fewer new cases in April 2020 compared with April 2019, raising concerns about the potential for diagnostic delay. Similar anxieties had been expressed related to delayed presentation of patients with T1DM. One survey of diabetes units in the UK reported that 20% of children and young people diagnosed with T1DM between 1 March and 30 June 2020 had had a delayed presentation. Reasons for this included fear of contracting SARS-CoV-2 as well as limited access to GP services.

Similarities between type 1 diabetes and childhood cancer presentations
While T1DM and CC cancer are different in terms of their presentations, we chose to investigate them together because they are both relatively rare, yet well recognised and potentially life-threatening conditions. We found no evidence that either of these conditions were associated...
Figure 3 Time to diagnosis for childhood cancer for leukaemia, CNS (Central Nervous System) tumour and all other tumour types combined. (A) Total diagnostic interval (TDI): interval between first symptom onset to diagnosis. (B) Patient interval (PI): time from initial symptom onset to first presentation to healthcare. (C) System interval (SI): time between first presentation to healthcare to diagnosis.
with delayed presentations associated with the pandemic. Other similarities include a higher PI during January–March 2020 and a shift from presentation via the general practitioner to the emergency department.

We demonstrated higher PI during January–March 2020 for patients with CC and T1DM. This may reflect a period of uncertainty for patients and healthcare systems in preparation for the first phase of the pandemic. There was widespread UK media coverage of the approaching pandemic and we hypothesise that this may have resulted in families initially avoiding healthcare services. Further work will be required to establish whether this hypothesis can be substantiated with evidence from the behaviour and beliefs of service users themselves. The subsequent reduction in PI during and after lockdown suggests no significant delay in caregivers seeking medical attention for children, which may reflect increased public health messaging that was not initially present during the lead up to lockdown and the pandemic.

While there was variability between units, there was evidence of a shift towards first presentations to ED from primary care, for patients with CC and T1DM. While we did not identify statistically significant changes, we recommend that each treatment centre evaluate any change in how their services have been accessed during the pandemic, to assist in future service planning.

**Type 1 diabetes**

A study of the North-West London Paediatric Diabetes Network between 23 March and 4 June 2020 reported an apparent increase in cases of new-onset T1DM in two of the five units. Overall, 21/30 children with a new diagnosis presented with DKA, 52% of which were severe. These are generally considered to represent high rates of both DKA and severe DKA in newly diagnosed patients. However, the number of children involved in this study was small, no comparisons were possible with other time periods and we were unable to replicate the findings.

In a large survey of 53 Italian paediatric diabetes centres, the number of newly diagnosed children with T1DM and DKA were similar to 2019. However, the proportion of all patients with T1DM who developed severe DKA was significantly greater in 2020 (44.3% vs 36.1%, p=0.03). Despite not being significant, the pattern of our results are similar to the Italian experience which demonstrated a 9% reduction in new diagnoses of T1DM when comparing January–July 2020 to January–July 2019. Our data showed a 7%–44% reduction in cases of T1DM, with a 27% decrease during March 2020 when national lockdown was announced. The incidence of DKA at presentation was stable between the measured time periods, however the incidence of severe DKA was slightly worse following lockdown (22% (April–July 2020) vs 12% (January–March 2020) vs 13% (January–July 2019)).

The increased incidence of severe DKA among patients diagnosed post lockdown, while not significant, is a concern. This finding is consistent with the Italian data and with other units in the UK. It initially appears to be counterintuitive when one takes into account the reduction in the TDI and PI post lockdown. However, it is well recognised that some children with T1DM can present acutely with rapid onset of ketoacidosis. The increased rate of severe DKA at presentation serves to emphasise the importance of the ongoing provision of public health campaigns to raise awareness of the symptoms of T1DM among parents/caregivers.

**Childhood cancer**

Overall, TDI for CCs was stable between the three time periods. Consistent with previously published evidence, the TDI for leukaemia was shorter than for CNS tumours,
suggesting that the COVID-19 pandemic did not disturb this pattern.

A large cross-sectional survey from the Paediatric Oncology East and Mediterranean Group reported that some centres noticed that all newly diagnosed patients experienced delays in diagnosis during the pandemic.21 This was thought to be due to: (1) patients refusing to present for essential visits for fear of contracting COVID-19; (2) hospital staff being relocated to other areas and (3) governmental decisions affecting the availability of public transport and freedom of travel. Although in the UK during the first lockdown the availability of public transport was decreased and in some tertiary oncology centres paediatric hospital staff were redeployed, our data does not support a similar situation in the participating centres.

Overall, 10% of new CC diagnoses in this study required intensive care within 7 days of admission, the majority of these had CNS tumours, most likely due to the requirement for early neurosurgery. From this we infer that patients diagnosed during the pandemic were not more unwell than if they had been diagnosed earlier. We recognise that intensive care admission resulting from treatment can occur in the early stages post diagnosis.22 Consequently, using intensive care admission may overestimate initial disease severity. Reassuringly, a CCLG Study reported that children with cancer and SARS-CoV-2 infection do not appear at increased risk of severe infection compared with the general paediatric population.23

Study limitations

Only four UK centres were involved, therefore the study lacked the ability to detect national variations in patterns of presentation. Given the retrospective nature of our study, we cannot exclude the possibility of incomplete areas of data collection, since that some of the children in the service evaluation will have been treated in more than one centre. We believe that this effect is both random and minimal across the centres. Our data collection approaches used a standardised electronic form replicated across all centres. Data were entered by individuals at each centre and double checked by the same individual at the point of entry to the database. Data were subsequently assessed and cleaned by the database administrator and any discrepancies or queries were sent back to the individual who had collected the data for resolution. With more resource we would have used double data entry techniques and the fact that we were unable to do this represents a limitation of our study.

Given the resources available for this service evaluation, we elected to collect comparison data for 1 year prior to the pandemic (2019). However, we recognise that fluctuation occurs and a longer period of pre-pandemic data collection would have provided greater insight into this variation. It was reassuring however that the incident cases of CC across the UK as a whole remained stable from 2013 to 2017.24

In view of the fluid situation of the pandemic, data collection was completed in July 2020 as we believed that timely presentation could inform local practice. We will continue data collection to account for the diagnostic lag for specific diseases including brain tumours. Data collection at a more comprehensive national level would also provide greater clarity on diagnostic intervals. Furthermore, it is important to establish whether subsequent public health measures are associated with longer time to diagnosis due to an evolving backlog of patient referrals across the UK.

CONCLUSIONS

This project was born out of a desire to understand the diagnostic intervals and severity of two life-changing childhood diagnoses during the COVID-19 pandemic. Our findings suggest that public health measures, imposed to control the spread of the pandemic during the first lockdown in the UK, were not associated with delayed diagnosis of CC or T1DM at participating centres. This is good news in the context of a pandemic that has been harmful to children’s health and well-being in many other ways. We believe that our study can play a key role in allaying parental and professional concern.

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Acknowledgements The authors would like to thank Dr Bob Phillips for his valuable input into the Caldicott approval application process and project setup at Leeds Teaching Hospitals NHS Trust. TR acknowledges the NIHR for funding his academic clinical lecturership. DS would like to acknowledge the NIHR for funding her doctoral research fellowship.

Contributors J-FL and DS were involved in the designing of the study, data collection form and planning the data analysis. RM, MB, KB, RMcL, NTC, TR, MD, PS and GW identified eligible cases. RM, EB, KB, RMcL, NTC, TR, AC, JL and GW collected data at local centres. J-FL conducted the statistical analysis. GW and RMcL wrote the first draft of the manuscript. GW, RMcL, J-FL, TR, MB, RM, MD and PS were involved in editing and reviewing the manuscript. All authors contributed to and approved the final manuscript. DW supervised the study.

Funding RTM was supported by a UK Research and Innovation (UKRI) Future Leaders Fellowship (MR/S017151/1).

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Funding RTM was supported by a UK Research and Innovation (UKRI) Future Leaders Fellowship (MR/S017151/1).

Competing interests None.

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Patient and public involvement statement The data were collected to inform healthcare professionals and the public about presentation route, timing and disease severity for children with newly diagnosed childhood cancer and type 1 diabetes during the COVID-19 pandemic. Due to the unprecedented, urgent need for the data, patients and the public were not involved.

Patient consent for publication Not required.

Ethics approval The protocol was approved by Caldicott guardians of all centres involved.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

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REFERENCES
9 CCLG ChildCancerSmart. Child cancer smart is a scientific 4-year research project that aims to reduce the time taken to diagnose cancer in children, teenagers and young adults, 2020. Available: https://www.cclg.org.uk/ChildCancerSmart