

Supplementary material 2 Details of respondents who rated questions in the interim survey (n=174)

| | Response | Patients/former patients (n=58) | Parents/relatives/ friends/partners (n=45) | Professionals (n=71) |
|---|---|---------------------------------|--|----------------------|
| Gender | Female | 42 (72%) | 39 (87%) | 57 (80%) |
| | Male | 16 (28%) | 6 (13%) | 13 (18%) |
| | Prefer not to answer | 0 (0%) | 0 (0%) | 1 (1%) |
| Ethnic group | White | 53 (91%) | 41 (91%) | 65 (92%) |
| | Asian or Asian British | 4 (7%) | 3 (7%) | 1 (1%) |
| | Black African, Black Caribbean or Black British | 0 (0%) | 0 (0%) | 1 (1%) |
| | Mixed/multiple ethnic groups | 1 (2%) | 0 (0%) | 2 (3%) |
| | Prefer not to answer | 0 (0%) | 1 (2%) | 2 (3%) |
| Age (years) | 13-15 | 1 (2%) | 0 (0%) | n/a |
| | 16-18 | 11 (19%) | 0 (0%) | n/a |
| | 19-24 | 27 (47%) | 4 (9%) | 2 (3%) |
| | 25-34 | 18 (31%) | 4 (9%) | 9 (13%) |
| | 35-44 | 1 (2%) | 7 (16%) | 26 (37%) |
| | 45-54 | 0 (0%) | 18 (40%) | 23 (32%) |
| | 55-64 | 0 (0%) | 9 (20%) | 10 (14%) |
| | 65+ | 0 (0%) | 2 (4%) | 0 (0%) |
| | | Prefer not to answer | 0 (0%) | 1 (2%) |
| Country of residence (patients/former patients/parents/relatives/friends/partners) | England | 53 (91%) | | 62 (87%) |
| | | | 31 (69%) | |
| Country of work (professionals) | Scotland | 3 (5%) | 9 (20%) | 4 (6%) |
| | Wales | 0 (0%) | 4 (9%) | 1 (1%) |
| | Northern Ireland | 2 (3%) | 0 (0%) | 2 (3%) |
| | Other | 0 (0%) | 1 (2%) | 1 (1%) |
| | Missing data | 0 (0%) | 0 (0%) | 1 (1%) |
| Cancer first diagnosed with | Hodgkin's disease/lymphoma | 14 (24%) | 10 (22%) | n/a |
| | Leukaemia | 12 (21%) | 7 (16%) | n/a |

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|---------------------------|---|----------|----------|-----|
| | Bone tumour (sarcoma) | 2 (3%) | 7 (16%) | n/a |
| | Non-Hodgkin's Lymphoma | 1 (2%) | 4 (9%) | n/a |
| | Brain or spinal cord | 8 (14%) | 3 (7%) | n/a |
| | Soft tissue tumour (sarcoma) | 6 (10%) | 4 (9%) | n/a |
| | Ovarian | 1 (2%) | 0 (0%) | n/a |
| | Thyroid | 1 (2%) | 1 (2%) | n/a |
| | Testicular | 4 (7%) | 3 (7%) | n/a |
| | Breast | 1 (2%) | 0 (0%) | n/a |
| | Cervical | 1 (2%) | 0 (0%) | n/a |
| | Other | 7 (12%) | 6 (13%) | n/a |
| Current situation* | Survivor/Follow-up care | 40 (69%) | 10 (22%) | n/a |
| | End of treatment | 5 (9%) | 5 (11%) | n/a |
| | On treatment | 4 (7%) | 10 (22%) | n/a |
| | Relapsed | 2 (3%) | 2 (4%) | n/a |
| | Palliative and end of life care | 1 (2%) | 0 (0%) | n/a |
| | Deceased | n/a | 11 (24%) | n/a |
| | End of treatment, Survivor/Follow-up care | 2 (3%) | 3 (7%) | n/a |
| | On treatment, Relapsed | 0 (0%) | 1 (2%) | n/a |
| | End of treatment, Relapsed | 0 (0%) | 1 (2%) | n/a |
| | On treatment, End of treatment | 0 (0%) | 1 (2%) | n/a |
| | On treatment, Survivor/Follow-up care | 1 (2%) | 1 (2%) | n/a |
| | Not sure | 3 (5%) | 0 (0%) | n/a |

*Participants could select more than one response