Methodology

All.Can Patient Survey

May 2019

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Introduction

This document details the methodology used to conduct the All.Can patient survey. The aim of the All.Can patient survey was to obtain a robust evidence base on where patients encountered inefficiency in their care – where inefficiency was defined as resources that are not focused on what matters to patients.

Who conducted the study?

Quality Health (https://www.quality-health.co.uk/), an expert survey provider, was commissioned by All.Can international to conduct this study. The study was managed by the All.Can international secretariat. The All.Can international research and evidence working group (members listed online here) were responsible for reviewing and commenting on all study outputs, as well as approving all final materials. All.Can national initiatives were involved in the drafting and approval of all materials pertaining to their countries' survey(s) – and they worked collaboratively with All.Can international on all stages of international rollout. The survey was carried out in line with the Code of Conduct set out by the Market Research Society in the UK and the equivalent European organisations.

About All.Can international

All.Can is an international, multi-stakeholder policy initiative striving to improve efficiency and sustainability in cancer care by focusing on what matters to patients. The initiative aims to identify ways we can optimise the use of resources in cancer care.

All.Can comprises leading representatives from patient organisations, policymakers, healthcare professionals, research and industry; and consists of All.Can international, plus All.Can national initiatives currently established in 12 countries.

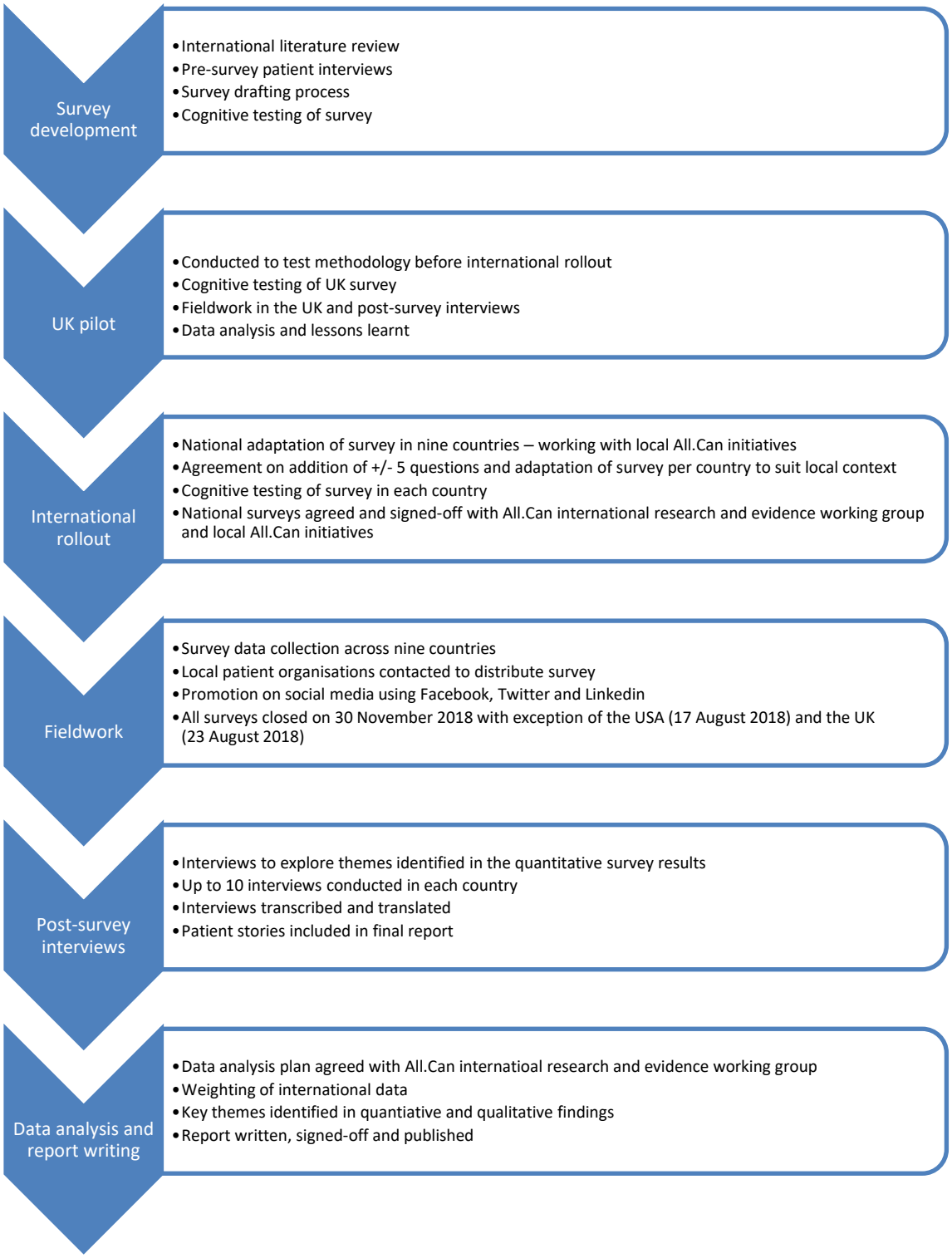
Overview of study

The study involved a number of different steps (outlined in *Figure 1*):

- Survey development – literature review, interviews, drafting and testing
- UK pilot – initial study conducted to test methodology before international rollout
- International rollout of survey in nine countries across the globe
- Fieldwork and data collection
- Post-survey interviews to test themes found in the survey results
- Data analysis and report writing – analysis and write up of findings

This methodology document describes each step in greater detail.

Figure 1. Overview of steps taken to execute the study



1 Survey development

This section outlines the steps taken to draft the All.Can patient survey, which aimed to provide a comprehensive picture of patient perspectives on where waste and inefficiency exist in cancer care, looking across the cancer care pathway. Our goal was to reach 300 to 400 patients per country.[1]

The steps taken to develop the survey were:

1. International literature review
2. Pre-survey interviews
3. Drafting process
4. Cognitive testing

1.1 International literature review

In order to inform the topics and issues to test through the patient survey, an international literature review was carried out, attempting to summarise evidence collected from published literature relating to patients' perspectives on waste and inefficiency in cancer care.

It included:

- international evidence on waste and inefficiency in cancer systems, from published literature from international organisations, journals and cancer registries
- additional evidence from survey data and freeform comments already held by Quality Health from previous cancer surveys
- a re-examination of evidence already collected and published by All.Can in its initial policy report.

The common themes identified across the above sources were:

- Poor communication and lack of discussion and co-determination between clinicians and patients
- Lack of accessible, understandable information to patients
- Delays in diagnosis and across the treatment pathway
- Administrative inefficiencies e.g. lost/mislaid referrals, poor coordination of care within/between elements of healthcare system, poor follow-up care after treatment
- Wasteful treatment e.g. expensive treatment where there are cheaper options (e.g. generic drugs vs. originator brands), treatment with limited clinical impact, treatment with unacceptable side effects, overuse of clinical marker tests
- Adverse events e.g. misdiagnosis caused by errors in reporting test results, failure to identify important symptoms
- Lack of appropriate treatment options, e.g. because medicines/treatments not available for financial/regulatory reasons
- Inequities and/or lack of treatment caused by payment systems
- Individual factors affecting particular groups
- Lack of data collection/capacity by governments and (inter)national agencies
- Missed opportunities around clinical trials/research.

[1] The final number of respondents was 3,981 for the overall international survey. See *Table 3* (page 19) for a breakdown of respondents by country.

1.2 Pre-survey interviews

The aim of the pre-survey patient interviews was to explore patients' experiences, inform the development of the quantitative survey questions, test a set of emerging themes which had already been identified as part of a separate literature review and build a range of case studies and patients' stories focusing on their views of waste and inefficiency.

Timelines

The pre-survey patient interviews took part during October and November 2017, in order that the findings could be considered, and questions formulated for possible inclusion in the final survey – as the intention was that the learning from the interviews would be used to feed into the design of the survey used for the quantitative survey.

Patient selection

Five patients were selected for pre-survey interviews, recruited (non-randomly) through current contacts with UK charities and patient groups. They were told that they would be invited to take part an interview via phone (or if they preferred, via Skype, Facetime or face-to-face). The interview took around 1–2 hours. No incentivisation was given to take part. They were offered the opportunity to speak directly to the interviewer before the interview to ask questions and to help build an initial rapport. Patients were told that there would be a particular focus in the interview questions about waste and inefficiency in cancer care. Following this initial contact, a convenient time was agreed for the interview to take place. The patients were able to choose whatever time they preferred, be that during the day, during the evening, or at the weekend.

The selection of patients was made to ensure:

- five different cancer types
- an even (as far as possible) mix of genders
- patients from different ethnic groups
- patients from different parts of the UK
- a mix of age groups
- as broad a range of experience as possible in terms of treatment types/route to diagnosis
- different phases and stages of cancer treatment.[2]

Interview process

The interviews were carried out by trained qualitative researchers, with specific training and experience in interviewing cancer patients.

The interviews were carried out in a semi-structured format. This means that there was a guide to the topics that would be covered through the course of the conversation, with some specific questions identified. The interviewer was free to follow different paths of the conversation that emerged and to prompt the interviewee to clarify and expand on relevant points as they arose.

The interviewer was free to gauge carefully how to run the interview to gain the best results from each of the patients, based on how willing they were to talk about their experiences, how confident they were, and how articulate they were.

[2] Specific details of patients are not given here to protect their identity.

The structure was as follows:

- An initial introduction on the scope of the interview
- A simple introductory question first, to allow the patient to gain confidence as well as for the interviewer to make an initial assessment about how the patient would prefer to be interviewed – for example, if they were confident enough to speak freely and easily or if they would require a slightly more structured approach with greater use of prompts
- The structure of the interview was deliberately designed to mirror a typical patient journey from first suspecting something is wrong, through to diagnosis, treatment and care, impact on life/work/family, post initial treatment etc.
- There were no specific questions about waste and inefficiency until the end of each of the sections of the interview – this was deliberately so, to ensure that patients were not influenced into speaking only about what they may think of as obvious examples of waste and inefficiency
- There was a section at the end which asked more general questions about waste and inefficiency and the patients' views on what they thought could be done to tackle these, as well as advice they may give to another patient who is at the start of their journey.

This format and structure were deliberately designed to facilitate a natural flow of dialogue while still allowing the collection of structured data.

Interviews were recorded with the patient's consent along with detailed notes during the conversation, to provide a non-verbatim transcript of each interview. This allowed for a concise report to be produced, using direct quotes where appropriate, alongside paraphrasing of patient's comments. All interviewees were given a copy of the first draft report so that they could check and agree that it was an accurate account of what they said.

Output

Quality Health provided a comprehensive (anonymised) report including:

- Executive summary
- Key themes arising out of the interviews
- Participant details and demographics (n.b. not personal identifiable details)
- Non-verbatim transcript of each interview
- Links between patient comments and themes arising out of literature review
- Recommendations for questions to be considered for inclusion in the quantitative survey.

1.3 Drafting process

In addition to the literature review and pre-survey interviews described above, the survey questionnaire was drafted drawing on:

- feedback from All.Can members at various consultation meetings, the European Health Forum Gastein All.Can policy forum (2017), and the International Brain Tumour Alliance conference All.Can patient masterclass (2017)
- Quality Health's experience of survey design and previous work with cancer patients.

The draft survey was circulated and approved by the All.Can international research and evidence working group before testing and validation took place.

1.4 Cognitive testing

The survey underwent a rigorous process of testing in order to ensure it was a valid method of measuring patients' views on waste and inefficiency. The validation process included two steps:

- **Academic/expert review** to ensure that the content of the survey was valid, carried out by recognised subject-matter experts (identified through the All.Can international research and evidence working group) to assess whether the questions were appropriate, reflective of current practice and would elicit the required responses
- **Cognitive testing with patients** to test whether the survey appeared to measure what it was supposed to measure, according to the survey participants. This included assessing how relevant the respondents felt the survey was, whether it was simple and easy to complete, whether it covered all appropriate areas of the patients' experience, and their understanding of the terms 'waste' and 'inefficiency'. This was carried out with 12 volunteers, recruited using a range of different sources including:
    - Quality Health's current contact list including a number of cancer charities
    - Contacts who form part of the All.Can network and membership
    - Macmillan's Cancer Patient Voices service – which allows organisations to advertise opportunities for cancer patients to volunteer
    - Social media networks as appropriate.

Due to this recruitment methodology, this was not a truly random sample of patients. However, the aim was to ensure a broad mix of volunteers across different cancer types, genders, ethnic groups, age groups and experiences.

No incentive was given to take part, and the cognitive testing process took place as follows:

- Volunteers were contacted either by email or phone (depending on their preference) to be introduced to the study and the person who would be carrying out the interview
- They were given the opportunity to ask any questions
- If they wanted to think about whether they wanted to take part, they were given this option
- They were sent a copy of the survey either by post or email
- They were asked to complete the survey as though they were doing so 'under normal circumstances'
- Once they had completed the survey, a convenient time to talk through their answers was agreed
- An interview structure was devised to detail the particular points which needed to be probed during the interview
- A write up of patients' comments was provided for each question with recommendations on amendments.

Review of the testing and validation outcome

A written report was provided, summarising the comments made on a question-by-question basis. Alongside this was a recommendation for amendments or changes to the questions or answer options. The recommendations were circulated to the All.Can international research and evidence working group for discussion and agreement as necessary.

2 UK pilot

Aim

The overall aim of the UK pilot was to test the survey described above, and the overall study methodology, before embarking on the international rollout phase. This section describes the UK pilot process and the key lessons learnt.

Recruitment of respondents

The recruitment of respondents took place via a range of organisations and networks, using a variety of media. Respondents accessed the link and information regarding the survey through seeing promotional materials distributed online (Facebook, Twitter, LinkedIn), by word of mouth, and through other networks. The list of organisations and media is extensive, but can be summarised as follows:

- Cancer charities
- Patient organisations
- Umbrella organisations
- Nursing organisations
- Other health-related organisations
- Additional organisations and contacts identified via working group members.

Each organisation was contacted in the most appropriate manner, usually either by phone or email in the first instance. Each organisation which agreed to take part in promotion was provided with a set of materials which could be used to populate social media, website/s, printed material, and newsletters/email distribution lists.

Fieldwork

The UK pilot survey went live online on 31 January 2018 and closed on 23 August 2018.

Post-survey interviews

There were five interviews with UK patients (in addition to the pre-survey interviews), which comprised a follow-up to the quantitative survey portion of the pilot. The purpose of these interviews was:

- to explore in more detail patients' experiences focusing on waste and inefficiency and in particular areas which have arisen out of the quantitative survey responses
- to build a range of case studies and patients' stories focusing on their views on waste and inefficiency.

Recruitment for post-survey interviews

Patients who completed the survey were asked whether they would agree to a follow-up interview, although it was made clear that not all patients volunteering for interviews would ultimately be interviewed. Five people were eventually selected for interviews based on their ability to identify and describe inefficiency and waste in care in their survey responses.

The interview process mirrored the one followed for the pre-survey interviews. The interview structure was adjusted to take into account the responses that the patient had previously provided and the reasons for their selection out of those volunteering. The post-survey interviews took place after the quantitative fieldwork period.

Key lessons learnt from the UK pilot

The purpose of the UK pilot was to test the survey and study methodology before the international rollout. Key lessons learnt informed the next phase of work. These are outlined below:

- The survey structure worked well, and elicited responses to virtually every question.
- The majority of respondents were happy to answer the open-ended questions as well as the closed-ended questions.
- Sufficient respondents were happy to be contacted again, which meant it would be possible to conduct post-survey interviews at a later stage, by contacting patients to volunteer after they completed the survey.
- Using the outlined recruitment strategy, we were able to secure respondents from across a range of different cancer types (although it was not equally spread according to prevalence data – so adjustments had to be made in recruitment according to these numbers).

However, the number of respondents in the UK was lower than anticipated due to a slow uptake of the survey by local patient organisations. In response, the original target of up to 1,250 responses per country was revised to 300–400, with plans to engage patient organisations in each country earlier to elicit their support. In addition, the UK pilot had to be extended a number of times to ensure there was a sufficient number of responses achieved.

3 International roll-out

Following the UK pilot, and using the final survey that had been developed and tested as part of that process, the approach detailed above was replicated in each of the nine other countries taking part. The timelines were tailored to each country's needs and flexibility was allowed around the wording and content of small numbers of individual questions so as to accommodate different healthcare environments.

Key roles and responsibilities

Quality Health Project Manager

- To oversee and coordinate the launch of the survey in each country

QH country leads (researchers with language expertise working with Quality Health)

QH country leads were researchers recruited with language skills necessary for the work required in each participating survey country. They worked for Quality Health and carried out a range of day-to-day activities and research, including the following:

- Ongoing liaison and support with recruiting organisations, including researching contacts or working with country contact (see below) and with other organisations as necessary. This was on an ongoing basis through the course of the preparation for survey launch and the fieldwork phase
- Working on the dissemination plan for the survey in each country
- Tracking and recording the contacts made and social media and other activity around the dissemination of the survey where possible
- Carrying any cognitive testing necessary for new/amended country-specific questions, and reporting back on these

- Conducting the in-depth interviews and reporting back on findings.

Country contacts (based in each of the All.Can national initiatives)

- Key contact person at local level for All.Can. Additionally, responsible for addressing any questions directed to them by Quality Health and the country lead, as well as for final sign-off of materials/translations within each country (as appropriate)
- Where there was no country contact present, Quality Health aimed to identify and work with existing local networks/organisations to identify individuals who could assist (for example with sign-off of translations) as appropriate
- For a full list of All.Can national initiatives and their members, visit https://www.all-can.org/national-initiatives/.

Quality Health led on the set-up and implementation of the surveys in each country, calling on help and advice from colleagues, existing networks and organisations in each country as necessary and appropriate.

Process

The international roll-out included the following steps:

- Initial call with country contacts
- Scoping of language requirements and changes needed to survey
- Translating materials
- Cognitive testing
- Survey sign-off and development of website to host surveys.

I. Initial call with country contacts

An initial call was set up with each All.Can national initiative contact to introduce the team and to run through the plan for launch. This call had several aims:

- Discuss and agree on the timelines for the survey launch and any input needed from the All.Can country contact
- Discuss and agree on the changes to the survey needed to make the survey suitable for local use
- Discuss and agree the processes for sign-off of the translated local version (if appropriate) of the survey
- Discuss the initial dissemination plan for the survey and compile list of contacts
- Discuss any further questions that the country contact/s had around the survey
- Agree on the need/frequency for any further calls between the country contact/s and Quality Health
- Agree on the process for updating the country contact/s on progress and any issues, as well as the plan for mitigating those issues.

II. Scoping of language requirements and changes needed to surveys

The survey was conducted internationally across nine countries (in addition to the UK) and the language versions needed for each country were identified as follows:

- Sweden: Swedish
- Poland: Polish
- Canada: English, French
- France: French

- Italy: Italian
- Spain: Spanish
- Australia: English
- Belgium: French, German, and Dutch
- USA: English.

In addition, there was an international survey created in English, French, German and Spanish for anyone to complete, in countries not listed above. This was posted on the All.Can and Quality Health websites.

In addition to confirming the language requirements above with each country contact, we identified any specific issues regarding jargon or dialects which may need to be taken into account by translators; and, for example, particular issues related to differences in healthcare systems.

III. Translating materials

There was a standard 'suite' of materials translated for each country, which included:

- Survey (with amends as agreed)
- Emails to participating organisations within each country as appropriate
- Recruitment materials for dissemination to participating organisations
- Survey overview PowerPoint presentation.

Quality Health used a translation agency for the initial translation for each country. Following this, all materials were passed on to the QH country leads for review, and then to the country contacts for further comment and review (where appropriate).

QH country leads were responsible for liaising with country contacts on feedback on the translation and agreement/final say on any amends.

IV. Cognitive testing

Once the final version of the local survey was agreed in each country and the translation was complete, we undertook a process of cognitive testing with volunteer patients. The QH country lead carried out this process. The testing involved up to 10 patients per country, depending on people's availability. These were non-randomised, and no incentives were offered.

The key aim of the testing was to ensure that the translation of the survey had been carried out correctly and that patients understood the questions and were able to answer them easily.

The amount of testing done was determined by the extent of comments coming back from each patient who was testing the survey, and the availability of patients to conduct cognitive testing. The process included:

- Quality Health and QH country lead liaising with country contact on recruitment of patients for cognitive testing
- QH country lead sourcing patients using the range of contacts already established
- Quality Health and QH country lead ensuring suitable diversity of participating patients in terms of types of cancer/stage of disease
- QH country lead:
    - contacting the patients and sending instructions
    - carrying out cognitive testing with patients and recording feedback on survey
    - reporting back to Quality Health and country contact on any issues requiring attention
- Quality Health and QH country lead agreeing on any changes required in the survey

- Liaison with appropriate people in agreement with the country contacts to ensure that any peer review which is necessary is carried out.

V. Survey sign-off and development of website to host surveys

Following cognitive testing and agreement on any amends, the final survey for each country was signed-off by Quality Health and the country contact (as appropriate) and the All.Can international research and evidence working group. The survey website was built – this was on a webpage of its own which Quality Health hosted and which could be accessed through the All.Can website.

4 Fieldwork

Dissemination of the survey

One of the key roles for Quality Health and the QH country lead was to establish a process and strategy for disseminating the survey for the international roll-out – and to give guidance to each individual country contact on appropriate recruitment methods. This included:

- discussion with country contact/s as appropriate around networks/organisations and existing contacts within the country
- desk research by QH country lead on establishing other contacts, and then making contact with them to discuss dissemination
- contact with known Quality Health/All.Can contacts/networks/organisations (e.g. European Cancer Patient Coalition (ECPC) and other umbrella organisations)
- recruiting directly through using social media and linking with appropriate organisations or individuals[3]
- paid social media campaigns in some countries to increase the survey reach outside our initial network of contacts
- recording and sharing as appropriate the plan for contacting organisations and keeping accurate records of who has been contacted and the outcome of the contact.

The survey was disseminated using the same strategy outlined in the UK pilot section.

Overview of countries and timelines

Table 1 outlines the countries participating in the survey, the languages created for each country and the fieldwork dates. Each survey took a specific amount of time to develop, therefore we released surveys as soon as they were signed-off by All.Can international and the All.Can national initiatives.

[3] As noted previously, this process has been managed differently in the case of the US survey.

Table 1. International rollout timelines for each country

Country	Languages	Fieldwork dates
Australia	English	12 July – 30 Nov 18
Belgium	English, French, Dutch	28 Aug – 30 Nov 18
Canada	English, French Canadian	13 June – 30 Nov 18
France	French	20 Sept – 30 Nov 18
Italy	Italian	27 Sept – 30 Nov 18
Poland	Polish	7 Jun – 30 Nov 18
Spain	Spanish	9 Oct – 30 Nov 18
Sweden	Swedish	20 Jul – 30 Nov 18
United Kingdom	English, Welsh	31 Jan – 23 Aug 18
United States	English	1 Jun – 17 Aug 18
Other	English, Spanish, German, French	31 May – 30 Nov 18

Respondent information

A total of 3,981 respondents participated in the survey. Table 2 provides further information on respondent characteristics.

Table 2. Respondent characteristics

Mean age	55 years old		
% patients by type of cancer	Brain / central nervous system	97	2%
	Breast	1,656	42%
	Colorectal / bowel	216	6%
	Gynaecological	415	11%
	Haematological	362	9%
	Head and neck	161	4%
	Lung	167	4%
	Prostate	144	4%
	Sarcoma	72	2%
	Skin	203	5%
	Oesophageal, stomach, pancreatic, liver, or gall bladder	123	3%
	Urological	186	5%
	Other *(Table 3)*	115	3%
% patients living with the disease in amount of years, at the time surveyed	Less than 1 year	964	25%
	1 to 5 years	1,706	44%
	More than 5 years	1,185	30%
	Don't know / can't remember	35	1%
	Unspecified (not included in %)	91	N/A

Table 3. Patient by type of cancer (other)

Summary	Frequency	% of Respondents
Missing[4]	57	1.43%
Multiple	9	0.23%
Not known[5]	9	0.23%
Adrenal	4	0.10%
Neuroendocrine	3	0.08%
Spinal	3	0.08%
Essential thrombocythemia	2	0.05%
Lymph gland cancer	2	0.05%
Neuroblastoma	2	0.05%
Skin and CML leukaemia	2	0.05%
Thymoma stage 4	2	0.05%
Ampullary cancer	1	0.03%
Appendix cancer pseudomyxoma peritonei	1	0.03%
Blasting plasmacytoid dendritic neoplasm	1	0.03%
Endocrine	1	0.03%
Fibroma	1	0.03%
Flat epithelial cancer	1	0.03%
Giant cell tumour	1	0.03%
Granulomatosis with polyangiitis	1	0.03%
Hydatid mole	1	0.03%
Lymph node-breast tissue cancer with metastases to the bone	1	0.03%
Merkel cell (skin)	1	0.03%
Olfactory neuroblastoma	1	0.03%
Ossifying fibro myxoid	1	0.03%
Osteochondroma (D16)	1	0.03%
PMP (pseudomyxoma peritonei)	1	0.03%
Retinoblastoma	1	0.03%
Squamous cancer of keratosis anus	1	0.03%
Squamous cell carcinoma (heterozygous, not keratinizing with an unknown primary focus)	1	0.03%
Thymoma	1	0.03%
Urachal adenocarcinoma	1	0.03%

[4] This refers to respondents who selected 'other' for cancer type but did not fill in a response.
[5] This refers to respondents who filled in a response under 'other', but it was not comprehensible.

5 Post-survey interviews

Alongside the surveys conducted in each country, there were up to 10 post-survey interviews conducted in each country where we were able to secure volunteers. The purpose and the process of carrying them out was the same as that for the UK pilot.

The post-survey interviews were summarised by the Quality Health researchers working in each language/country. The patients were given a copy of the transcript so that they could approve it. Each of the patients in the countries signed a consent form which means that extracts from the stories can be used for reporting purposes. We were successful in interviewing patients from most of the participating countries; however, were unable to interview any patients in Spain or France – this was because the pool of patients who responded to the survey was far lower than in other countries (<50 respondents).

The transcripts from the interviews were shortened and used as patient stories in the All.Can patient survey report, to complement the themes outlined in the quantitative report findings. Additional patient stories will also be featured on the All.Can website.

6 Data analysis and report writing

Data amalgamation

Results were obtained for surveys in each country, including responses to the 'generic' international version – totalling 3,981 responses. The international All.Can survey results – used to develop the results report – were produced by amalgamating all data, from all respondents in all countries.

Due to the bespoke nature of each individual country survey, only those questions that were comparable across all countries were included in the international results. Responses to questions unique to an individual country were not presented in the international results – only the country-level results.

Furthermore, respondents who stated within each country-level survey that they were not residents of the country in question, as well as those from the international survey, were not included in the country-level results. For this reason, total respondents per country may vary slightly between the country-level results and international results (*Table 4*).

Table 4. Number of respondents included in analysis for country and international datasets

	Country results	International results	Difference	Breakdown of additional respondents
Australia	850	861	+ 11	11 respondents who answered 'No' to 'Are you a resident of Australia?', excluded from bespoke results but included in international
Belgium	391	396	+ 5	3 respondents who answered 'No' to 'Are you a resident of Belgium?', excluded from bespoke results but included in international AND 2 respondents who completed the generic international survey
Canada	314	342	+ 28	27 respondents who answered 'No' to 'Are you a resident of Canada?', excluded from bespoke results but included in international AND 1 respondent who completed the generic international survey
France	50	55	+ 5	2 respondents who answered 'No' to 'Are you a resident of France?', excluded from bespoke results but included in international AND 3 respondents who completed the generic international survey
Italy	96	97	+ 1	1 respondent who completed the generic international survey
Poland	1135	1135	+ 0	No residence question in bespoke survey and no respondents completed generic international survey
Spain	49	50	+ 1	1 respondent who answered 'No' to 'Are you a resident of Spain?', excluded from bespoke results but included in international
Sweden	45	60	+ 15	14 respondents who answered 'No' to 'Are you a resident of Sweden?', excluded from bespoke results but included in international AND 1 respondent who completed the generic international survey
UK	322	360	+ 38	31 respondents who answered 'No' to 'Are you a resident of the UK?', excluded from bespoke results but included in international AND 7 respondents who completed the generic international survey
USA	497	513	+ 16	16 respondents who completed the generic international survey

Weighted international results

Quite different volumes and profiles of cancer patients responded in each country. Therefore, in order to present results from the overall respondent population, a set of weighted (quantitative) results was produced. The weighted international results show how the wider cancer population answered questions from the international survey.

These data were weighted by two factors:

- the representative cancer prevalence statistics within each participating country for the cancer types listed as response options in Question 31a: With what type of cancer were you first diagnosed?

- the general population statistics for each country as a proportion of the international total.

The international results were weighted to adjust for representative cancer survival population of each country, then for representative general population. The justification for applying weighting in this manner was to ensure that respondents from cancer types or countries underrepresented in the survey were not ignored, while those overrepresented did not unfairly dominate the scores.

Cancer prevalence weighting was applied first to adjust scores dependent on the national cancer prevalence population (*Table 4*) for each cancer type offered as a response in the international survey. Responses of cancer types with a higher prevalence population had a greater influence on overall scores, both at a national and international level. For example, if respondents from a specific cancer type with a higher national prevalence population generally gave positive answers, the overall scores for that question were lower (as higher implied greater inefficiencies or waste).

Country population weighting was applied to the cancer prevalence weighted scores dependent on the national population (*Table 4*) of each country. Responses from countries with a higher population had a greater influence on the cancer weighted scores at an international level. For example, if respondents from a specific country with a higher population generally gave positive answers, the overall scores for that question were lower (as higher implied greater inefficiencies or waste).

Data sources of weightings applied

Cancer prevalence data differed between the various All.Can countries. To keep the figures as consistent as possible, the European Commission EUROCARE-5 Study was used for all countries within the European Union. Data for all other countries was sourced from peer-reviewed national cancer reports (*Table 5*).

Table 5. Weighting applied to international results

Cancer prevalence population sources	
Country	Data source
Australia	Australian Institute of Health and Welfare – Cancer data in Australia 18th December 2018 https://www.aihw.gov.au/reports/cancer/cancer-compendium-information-trends-by-cancer/report-contents/summary
Canada	Statistics Canada Health Analysis Division – Journal 82-003-X Vol. 23 No. 1 – Canadian Trends in Cancer Prevalence https://www150.statcan.gc.ca/n1/pub/82-003-x/2012001/article/11616/tbl/tbla-eng.htm
USA	National Cancer Institute – SEER Cancer Statistics Review (CSR) 1975 - 2015 https://seer.cancer.gov/archive/csr/1975_2015/
Belgium France Italy Poland Spain Sweden UK	ECIS - European Cancer Information System Data Explorer https://ecis.jrc.ec.europa.eu/
Country population source	
All countries	United National Department of Economic and Social Affairs – World Population Prospects: The 2017 Revision https://www.un.org/development/desa/publications/world-population-prospects-the-2017-revision.html

Unweighted country results

Results for individual countries were produced using unweighted responses to individual country surveys (*Table 4*). Response numbers were insufficient to justify weighting these data.

Reporting of findings

The patient survey report contains both quantitative and qualitative findings.

Quantitative findings from the survey are based on responses to the closed-ended questions in the survey. Percentages are calculated after excluding those respondents that did not answer each particular question. All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total 100% because of this rounding.

As both patients and caregivers were eligible to complete the survey, the report refers to 'respondents' in all cases. For the international survey, percentages of 'respondents' refer to weighted data (see above).

Qualitative findings presented in the report are based on responses to open-ended questions. A thematic analysis was conducted of all open-ended responses to the survey, and key themes that emerged from these patient responses, as well as from the in-depth patient interviews conducted after completion of the survey, were identified. Final themes were agreed on by consensus of the All.Can international research and evidence working group. The most relevant quotes that supported these themes were then selected to illustrate these responses. These have been included under each relevant theme in the report.

The qualitative responses, which provided rich insights, were not quantified numerically, and so when describing qualitative responses the report refers to 'respondents' without specifying exact percentages.

Longer patient stories from the post-survey patient interviews are included throughout the report and were selected to amplify the themes in this report.

Country-level findings were included in the report only for countries where the survey had more than 50 responses: Australia, Belgium, Canada, Italy, Poland, the UK and USA. Those excluded were France, Sweden and Spain. These findings are unweighted because response numbers were insufficient to justify weighting and are, as such, not directly comparable between countries, as they represent different populations in each country.

For more information

To find out more about the survey and its deployment, please contact the Quality Health contacts listed below.

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