**Supplementary materials**

**Literature search**

Searches wereconducted between 4th December 2018 and 5th April 2019, using the sources listed below. The search was restricted to studies published from the 1st January 2009 onwards.

* Medline
* Embase
* CINAHL
* PsychINFO
* Cochrane Database of Systematic Reviews
* Cochrane Central Register of Controlled Trials
* DARE
* HTA database
* Current Controlled Trials
* Prospero database

The following shows the final search strategy used to search Medline. The strategy was adapted to search the other databases. All search strategies are available on request.

|  |  |
| --- | --- |
| **Medline** | |
| **ATMP Stem** | |
| 1 | exp "Cell- and Tissue-Based Therapy"/ |
| 2 | exp Genetic Therapy/ |
| 3 | Regenerative Medicine/ |
| 4 | Tissue Engineering/ |
| 5 | exp Gene Transfer Techniques/ |
| 6 | exp stem cells/ |
| 7 | exp Multipotent Stem Cells/ |
| 8 | Induced Pluripotent Stem Cells/ |
| 9 | exp Stromal Cells/ |
| 10 | stem cell research/ |
| 11 | (advanced therapy medicinal product$ or advanced therapy medicinal product$ or atmp$).tw. |
| 12 | regenerative medicine$.tw. |
| 13 | advanced therap$.tw. |
| 14 | (gene-therapy medicinal product$ or gene therapy medicinal product$ or gtmp$).tw. |
| 15 | (cell-therapy medicinal product$ or cell therapy medicinal product$ or ctmp$).tw. |
| 16 | (tissue engineered product$ or tissue-engineered product$ or tep or teps).tw. |
| 17 | (regenerative medicine advanced therap$ or rmat$).tw. |
| 18 | "human cells, tissues, and cellular and tissue-based products (HCT/Ps)".tw. |
| 19 | "human cells, tissues, and cellular and tissue-based product (HCT/P)".tw. |
| 20 | regenerative therap$.tw. |
| 21 | ("cell and gene therapy product" or "cell and gene therapy products" or cgtp or cgtps).tw. |
| 22 | or/1-21 |
| 23 | (Tisagenlecleucel or Kymriah or cart 19 or cart19 or "ctl 019" or ctl019).tw. |
| 24 | (Axicabtagene ciloleucel or Yescarta or kte c19 or ktec19).tw. |
| 25 | (Voretigene neparvovec-rzyl or Voretigene neparvovec?rzyl or Luxturna).tw. |
| 26 | (Talimogene laherparepvec or Imlygic or oncovex or t vec).tw. |
| 27 | (Strimvelis or gsk 2696273 or gsk2696273).tw. |
| 28 | Holoclar.tw. |
| 29 | MACI.tw. |
| 30 | (Provenge or sipuleucel t or apc 8015 or apc8015).tw. |
| 31 | (Glybera or alipogene tiparvovec or "amt 011" or amt011 or aav1 lpls447x).tw. |
| 32 | Zalmoxis.tw. |
| 33 | Spherox.tw. |
| 34 | or/23-33 |
| 35 | 22 or 34 |
| **Patient Filter (adapted SIGN Patient Issues filter)** | |
| 36 | ((patient$ or consumer$ or public) adj2 (decisi$ or decid$)).ti,ab. |
| 37 | "Patient Acceptance of Health Care"/ |
| 38 | exp attitude to health/ |
| 39 | Patient Preference/ |
| 40 | "patient satisfaction".ti. |
| 41 | exp health education/ |
| 42 | patient education as topic/ |
| 43 | health knowledge, attitudes, practice/ |
| 44 | "informed choice".ti,ab. |
| 45 | "shared decision making".ti,ab. |
| 46 | ("focus group" adj3 (patient$ or parent$ or famil$ or spouse$ or public)).ti,ab. |
| 47 | Consumer Advocacy/ |
| 48 | patient advocacy/ |
| 49 | exp professional-patient relations/ |
| 50 | ((patient$ or consumer$ or parent$ or famil$ or spouse$ or carer$ or public) adj (attitude$ or involvement or desir$ or perspective$ or activation or view$ or preference$ or experience$ or knowledge$ or understand$ or awareness$)).ti,ab. |
| 51 | exp decision making/ |
| 52 | exp communication/ |
| 53 | vignette\*.ti,ab. |
| 54 | "focus group$".ti,ab. |
| 55 | focus groups/ |
| 56 | exp empirical research/ |
| 57 | narration/ |
| 58 | (meta-ethnography or metaethnography).ti,ab. |
| 59 | grounded theor\*.ti,ab. |
| 60 | hermeneutic.ti,ab. |
| 61 | (inductive adj2 (analys\* or grounded or reasoning)).ti,ab. |
| 62 | (ethnograph\* or ethnological or ethnomethodol\* or ethnonursing research).ti,ab. |
| 63 | qualitative.ti. |
| 64 | exp qualitative research/ |
| 65 | (qualitative adj (research or stud\* or data)).ab. |
| 66 | exp Community Participation/ |
| 67 | Public Opinion/ |
| 68 | or/36-67 |
| 69 | 35 and 68 |
| 70 | limit 69 to yr="2009 -Current" |

**Supplementary Figure 1 PRISMA diagram showing literature search and selection process [1]**

Additional records identified through other sources  
(n =0 )

Records identified through database searching  
(n = 11,786)

Records after duplicates removed  
(n = 10,735)

Records screened  
(n = 10,735)

Records excluded  
(n =10,584 )

Studies included in qualitative synthesis  
(n = 33)

Additional studies identified through citation searching and also included qualitative synthesis (n = 2)

Full-text articles assessed for eligibility  
(n = 151)

Full-text articles excluded, with reasons  
(n =118 )

**Supplementary Table 1: Included studies**

**Full data extraction tables for the included studies are available from the authors on request.**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Author** | **Type of therapy** | **Participants** | **Indication** | **Country** | **Time of data collection** | **Design/method** | | **Reference** |
| Aked et al. (2017) | Cell | Patients | Ischaemic stroke | Sweden | Between 2014 and 2017 | Quantitative questionnaire | [2] | |
| Allum et al. (2017) | Cell | Public | General | Europe; USA; Canada | 2005 | Quantitative questionnaire | [3] | |
| Benjaminy et al. (2014) | Gene | Patients; clinicians; patient advocates | Choroideremia | Canada | June 2011 to June 2012 | Semi-structured interviews | [4] | |
| Blendon et al. (2016) | Gene | Public | General | US | 1986 to 2016 | Analysis of public opinion polls | [5] | |
| Bubela et al. (2012) | Cell | Media (newspaper articles) | General | Canada | 1990 to 2010 | Word frequency analysis | [6] | |
| Chung et al. (2014) | Cell | Patients; carers | Parkinson's disease | Korea | April 2013 to June 2013 | Questionnaire | [7] | |
| Clover et al. (2012) | Cell/tissue engineering | Patients | Burns | Ireland | 2010 | Quantitative questionnaire | [8] | |
| Cunningham et al. (2018) | Cell | Patients; carers | Stroke | UK | June to October 2016 | Focus group (conversation café) | [9] | |
| Dasgupta et al. (2014) | Cell | Public | General | USA | 2014 or earlier | Focus group | [10] | |
| Eijkholt et al. (2012) | Cell | Friends and family; patients | Spinal cord injury | Canada | June 2009 to February 2010 | Focus groups and interviews | [11] | |
| Einsiedel et al. (2009) | Cell | Patients; public; caregivers | General | Canada | 2009 or earlier - not specified | Focus groups | [12] | |
| Evans and Kelley (2011) | Cell | Public | General | USA | 2009 | Quantitative questionnaire | [13] | |
| Hodges et al. (2012) | Cell | Patients (pregnant women) | General and 15 specific disorders | Australia | 2009/2010 | Quantitative questionnaire | [14] | |
| Horch et al. (2016) | Cell | Public (firefighters) | Burns | Canada | 2016 or earlier | Mixed methods; quantitative online survey followed by a qualitative semi-structured interview | [15] | |
| Hudson and Orviska (2011) | Gene | Public | General | Europe | 2005 | Eurobarometer public opinion survey | [16] | |
| Jacob et al. (2015) | Cell | Patients | Spinal cord injury | Canada; USA | 2015 or earlier | Qualitative interviews | [17] | |
| Jannetta et al. (2010) | Gene | Patients | Cystic fibrosis | UK | 2009 or earlier - not specified | Qualitative interviews | [18] | |
| Kim et al. (2013) | Cell | Patients | Ischaemic stroke | South Korea | Jan to May 2011 | Quantitative and qualitative interviews | [19] | |
| King et al. (2010) | Cell | Patient; Public | HIV/AIDs | USA | 2010 or earlier | Focus groups | [20] | |
| King and Lyall (2018) | Cell | Public | Blood transfusion | Scotland | 2011 to 2017 | Ethnographic study; 15 interviews and 12 focus groups | [21] | |
| Nelissen et al. (2016) | Cell | Patients; public | Cancer | Belgium | 2016 or earlier | Cross sectional survey | [22] | |
| Nelles et al. (2015) | Gene | Patients | Genetic eye disease | Germany | 2015 or earlier | Quantitative questionnaires and qualitative interviews | [23] | |
| Nisbet et al. (2014) | Cell | Public | General | USA | 2002 to 2010 | Quantitative surveys | [24] | |
| Peay et al. (2018) | Gene | Patients; carers | Duchenne Muscular Dystrophy | USA | March to May 2017 | Qualitative interviews | [25] | |
| Rachul and Caulfield (2015) | Cell | Public | General | USA; Canada | Earlier than February 2015 | Qualitative analysis of news media articles and readers' comments | [26] | |
| Robillard et al. (2013) | Gene | Public | General | Canada | 2006-2010 | Content analysis | [27] | |
| Robillard et al. (2014) | Gene | Public | General | USA; Canada | 2014 or earlier | Online survey | [28] | |
| Shineha et al. (2018) | Cell | Public; scientists | General | Japan | October 2015 to March 2016 | Quantitative questionnaire | [29] | |
| Sipp D. (2017) | Cell | Public | General | USA | 2016 | Content analysis | [30] | |
| Stewart et al. (2015) | Cell | Public | General | UK | Aug to Sep 2014 | Qualitative interviews and questionnaire | [31] | |
| Strong H et al. (2017) | Gene | Patients | Sickle cell | USA | 2010-2012 | Focus groups | [32] | |
| Tanner et al. (2017) | Cell | Patients; carers; clinicians; patient advocates | General | Australia | 2012-2014 | Qualitative interviews | [33] | |
| Vicsek and Gergely (2011) | Cell | Media newspaper articles; public | General | Hungary | 2006 to 2008 | Qualitative content analysis and focus groups | [34] | |
| Wang et al. (2017) | Gene | Public; clinicians | General | China | August 2016 to November 2016 | Online survey | [35] | |
| Wright et al. (2016) | Cell | Patients | Post-obstetric incontinence | UK | 2016 or earlier | Quantitative questionnaire with some free text response options | [36] | |

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