

Is the rise of crowdfunding for medical expenses in the UK symptomatic of systemic gaps in health and social care?

Isabel Pifarré Coutrot, Richard Smith, Laura Cornelsen

Abstract

Crowdfunding for medical care is a new phenomenon but increasingly used by individuals to seek financial help to cover the costs of health care. Ethical concerns have been raised about medical crowdfunding, including implications for equity, resource allocation, medical decision-making, the promotion of non-evidence based therapies, platforms' lack of transparency and corporate interests. Medical crowdfunding efforts may point to shortcomings in health service provision, but they tend to have wider motivations and implications. However, there is no firm evidence base for establishing answers to even the most basic questions; such as who is seeking funds, for what, where and why? In this Essay we provide an introduction to medical crowdfunding in the United Kingdom (UK). We synthesise what is currently known and the insights that might be gained from an exploratory review of 400 medical crowdfunding campaigns on the GoFundMe UK website: for instance whether medical crowdfunding occurs in response to gaps in service provision, supports 'queue jumping' and how it relates to 'medical tourism'. We conclude with a call for research on medical crowdfunding in the UK (and elsewhere) as a means to better understand patients' perceived or actual unmet need for health and social care and inform policy development.

Introduction

Medical crowdfunding is a small but rapidly growing phenomenon whereby individual health care costs are (co-)funded by raising money from a large number of people who make (relatively small) individual contributions using an open Internet platform. GoFundMe is one of the largest platforms for medical fundraising using crowdfunding,¹ covering a wide range of medical (and social) care issues for which people seek financial support. Evidence concerning the motivations for and implications of medical crowdfunding for the individual and the health system is slowly emerging, mostly from Canada² and the USA.^{3,4} In this Essay we consider the possible impacts of medical crowdfunding in the UK, which operates a state funded universal health care system. We begin with an overview of the core concerns around medical crowdfunding that have been discussed in the literature to date and supplement this with an exploratory review of funding campaigns on the GoFundMe UK website, focusing on the nature of health related crowdfunders and their reasons to raise funds. We then discuss the potential for further research to inform policy and address gaps in the health system that may lead people to seek medical fundraising online.

Medical crowdfunding raises equity and ethical concerns

Available literature suggests that successful crowdfunders are more likely to have a strong social network, good communication skills, and the ability to make use of technology to reach social media, which raises important equity concerns.⁴ This means that those who could strongly advocate for systemic changes instead direct this potential to their own individual case. This might leave behind the most vulnerable who are not in the best position to advocate for themselves, further increasing inequities.^{2,3,5}

Crowdfunding also modifies how health care resources are allocated, as the amount of funds collected is based on the judgement of donors and resources may not be fairly distributed.⁴ Decision to donate, and hence what to allocate additional funds towards, are not based on priorities, medical conditions or legitimacy of the demands, but on abstract individual preferences that depend on external attributes (for instance, physical appearance, sex, age and race) and the ability to tell a story that appeals to donors' generosity.⁶

Medical crowdfunding may further challenge clinicians' authority. This is illustrated by the widely reported case of Charlie Gard⁷, a British child born in 2016 who was diagnosed with a rare genetic disorder at a few months of age. The disorder, encephalomyopathic mitochondrial DNA depletion syndrome, had no effective treatment and, thus, a poor prognosis. In brief, the responsible UK hospital agreed with an American neurologist on trying an experimental treatment at National Health Service (NHS) expenses but as Charlie's condition had worsened in the meantime, the UK team advised the family to end life support and provide palliative care. His parents then raised £1.3 million on crowdfunding platforms for their son to be treated in the USA. This unleashed a series of lawsuits between the treating hospital and Charlie's parents, leading to a ruling by four courts, including the European Court of Human Rights that it would be in Charlie's best interest to not receive experimental therapy overseas. The American neurologist finally visited Charlie in July 2017 and agreed that it was too late to attempt the treatment and to withdraw life support. Life support was suspended and Charlie died the next day. While this much-publicized case reopened the debate around medical authority on the right to die or live for terminally-ill patients, it has wider implications as with crowdfunding, patients and their relatives have alternative means to self-fund treatment privately at home or abroad.

Crowdfunding platforms lack transparency.¹ Campaigners and donors do not have equal access to information as the donor's knowledge is mainly based on disclosures from fundraisers and there have been instances of fraudulent campaigns and money laundering.^{1,8} Fundraising platforms cannot guarantee the accuracy of the campaign content or whether raised funds do indeed support the campaign cause, or whether the proposed treatment is medically realistic and coherent as well as safe to patients and others. There is also lack of transparency about the way the platform is organised in terms of promoting crowdfunders and displaying campaigns, which may create another form of inequity.^{1,9} Equally, donors supporting treatment through crowdfunding may be less likely to donate to medical charities such as Macmillan Cancer support or Great Ormond Street Hospital which are traditionally linked to supporting health and health care.

Finally, there are regulatory uncertainties around crowdfunding platforms. From 2018, GoFundMe UK has been generating revenue that relies on voluntary gratuities from donors (at a suggested 10-20% per donation), replacing the initial 5% platform fee that campaigners were required to pay on total funds collected.^{10,11} Still, GoFundMe remains a business and as such it may have a financial incentive to help individuals to self-fund their care, especially for more costly treatments that may generate more donations (and more added income from gratuities). Related concerns arise around conflict of interest where individuals' fundraising causes contravene platform owners' political or moral views, leading them to censor campaigns such as in the case of women fundraising for abortions in the USA.⁸

Medical crowdfunding in the UK

Newman (2018)¹² described how, in the UK, crowdfunding has led to patients spending donated money on alternative and unproven treatments for advanced cancer, but, overall,

this topic has so far received little to no attention in the UK. Informed by a review of 400 campaigns for medical causes on the GoFundMe UK website (Box 1), the following examines the nature and scope of medical fundraising in the UK as identified from this rapid review.

Box 1. Review of GoFundMe UK: summary of the methodology

We carried out a 'spot sample' of 400 campaigns for medical causes posted and publicly available on 3rd and 4th of July 2018 on the GoFundMe UK website. Included campaigns had to have a human beneficiary who is UK resident; campaign funds were to benefit no more than two individuals and campaign pages provided information about sex, age range, nature of medical condition and type of help requested. The website presents campaigns in descending order according to the amount of money raised, ranging, for the first 400 campaigns from £185,227 to £1,429, covering diverse profiles of crowdfunding campaigns. By including the first 400 campaigns only, our analysis likely only included the most successful campaigns in terms of funds raised. However, these campaigns tended to be better documented, allowing for more detailed examination. We extracted data on: region of residence; level of funds requested and collected; number of donors and year the campaign was created; this data was directly available from individual campaigns' formats. In addition, we extracted information on age range and sex of the campaigner; the medical cause (disease or condition); and the purpose of the campaign. This data was derived from narratives provided in individual campaigns and subject to interpretation.

Who are fundraisers in the UK, what funding do they request and raise?

Fundraisers of the first 400 campaigns had collected a total of £6m from 113,202 donors as at 4 July 2018. The vast majority (80%) of the campaigns had requested funds of up to £50,000. One third of the campaigns had already reached or exceeded their targeted funds, while

another third had met between 50% and 99% of their target (Figure 1). Campaigns requesting the highest amount of funds were to finance treatment abroad, private care in the UK and medical repatriation of UK residents who had experienced a health issue while abroad.

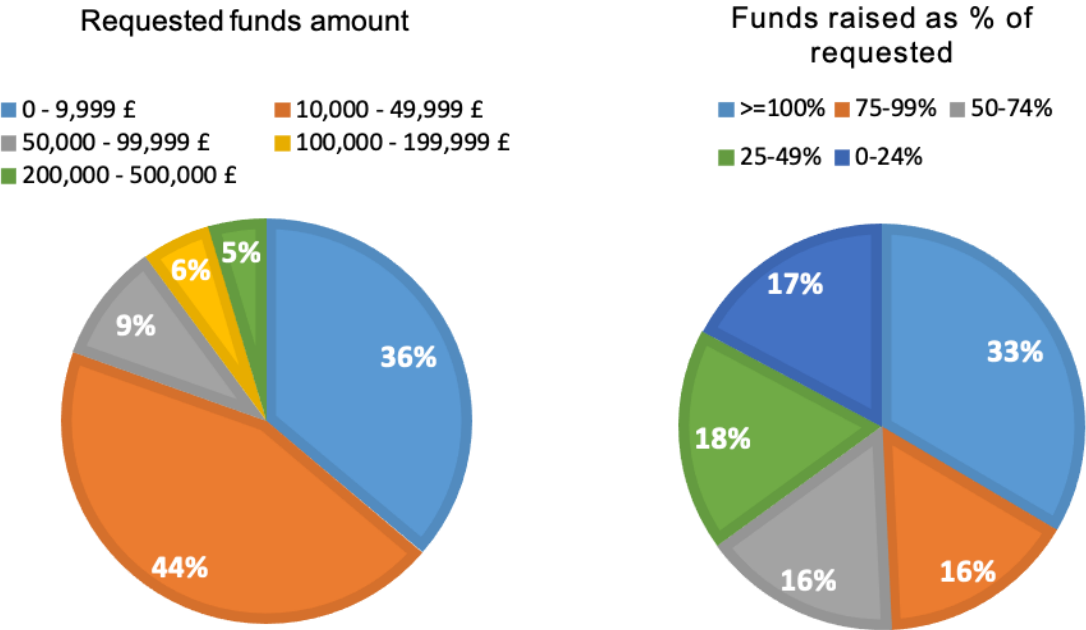


Figure 1. Fund requested and raised for medical purposes by the first 400 campaigns on the GoFundMe UK website (4 July 2018)

The gender distribution of fund seekers was equal, and, geographically, marginally more campaigns originated in London, the south and west of England. On average, two thirds of campaigns sought funds for adults but with some variation across requests. For example, adults represented 81% of recipients with neurological conditions, 74% of those with cancer and only 34% of those with rare genetic diseases.

What care services are medical fundraising campaigns seeking?

Half of the campaigns (n=204) requested funds for cancer care while the remainder (n=196) requested financial support to cover costs arising from a wide range of medical issues,

including rare genetic conditions (13%), neurological conditions (8%), accidents (7%) and less frequently for perinatal events, spinal conditions, infectious diseases, cardiovascular diseases, autoimmune diseases, mental health issues, sex reassignment therapy, renal conditions, eye conditions, respiratory conditions and cosmetic procedures.

Among cancer sites, those of the brain and central nervous system formed the largest group (21%), followed by breast cancer (13%), sarcoma (11%), bowel cancer (8%) and leukemia (8%). Around one-third (32%) of cancer campaigns were for patients with disclosed stage 4 cancer.

The most common purpose for seeking funds was to get treatment abroad (34% of the 400 campaigns), followed by alleviating the financial burden associated with ill health (23%), supporting private care in the UK (19%) and equipment (18%). Campaigns requesting funds for alternative therapies (conventional or non-conventional therapies with no or limited proof of efficacy) represented less than 12% of reviewed campaigns. Twelve per cent of campaigns were related to costs arising at the end-of-life (Figure 2).

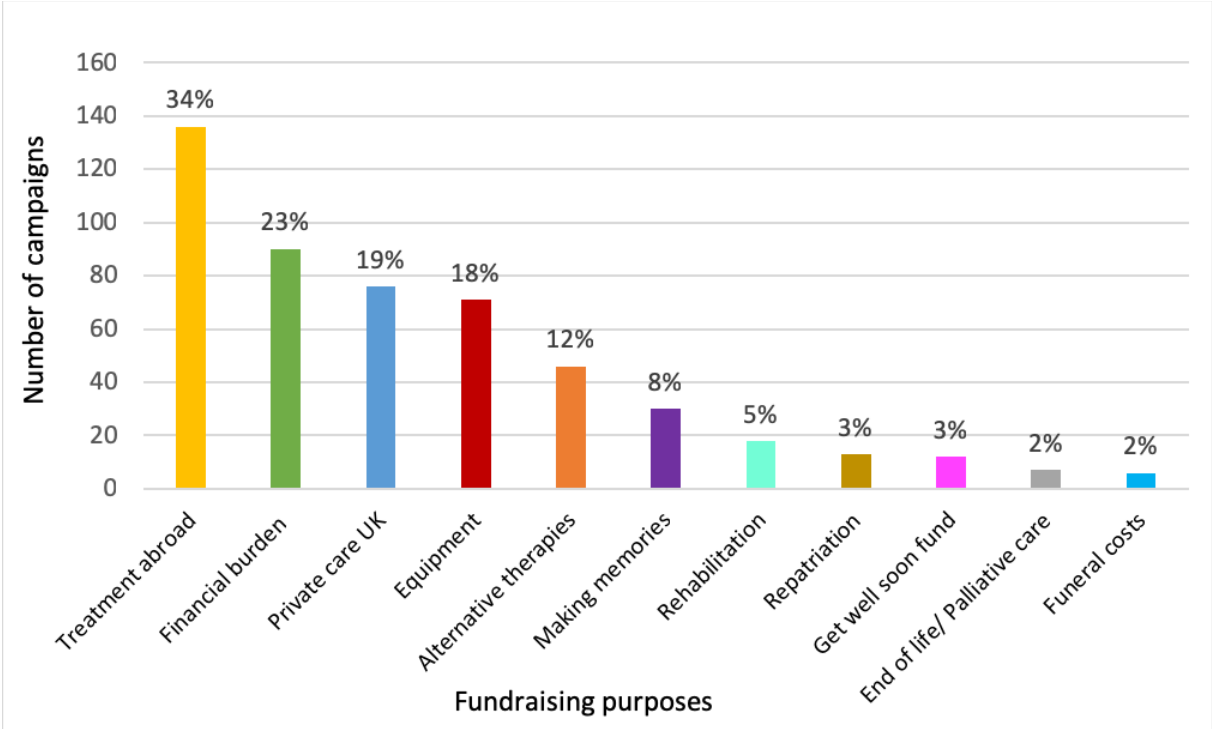


Figure 2. Fundraising purposes of the first 400 medical campaigns on the GoFundMe UK website (4 July 2018)

Note: one campaign can have more than one fundraising purpose

What sort of care is sought from abroad, and why?

The most common treatments for which funding was sought abroad were immunotherapy (20%), stem cell therapy (16%), surgery (14%) and alternative therapies (12%). The majority of campaigns sought treatment in Germany (36%) or the USA (31%), with another 5% seeking treatment in Russia or Mexico. Among the 46 campaigns seeking support for treatment in Germany, the majority (37%) were for immunotherapy and 21% for alternative therapies. Those seeking support for treatment in the US predominantly requested funds for proton beam therapy (18%), highly specialised consultations or therapy (for instance paediatricians or Lyme disease specialists) (18%) and surgery (16%).

What sort of financial help is sought in the UK, and why?

Of the 400 campaigns sampled, 76 asked for funds to support private care in the UK. These were most commonly for surgery or other procedures (33%), followed by immunotherapy (24%) and other cancer care, including radiotherapy (11%). The main reason for seeking support cited was the urgency and need to bypass NHS waiting lists, with fundraisers expressing fears that their health condition would deteriorate further and putting their life at risk by the time the NHS takes care of them.

Among the 72 campaigns seeking funding to get equipment, 39% of recipients had a rare genetic disease, and of these, a majority (66%) were to benefit children. The most common request for equipment related to all-terrain wheelchairs to support mobility and

independence of those with disabilities. Of the 400 campaigns, 20 (5%) sought funding to access rehabilitation therapies.

Of the 400 campaigns, ninety-two (23%) sought financial help to cope with costs beyond treatment, such as loss of income, travelling expenses to get care and the inability to pay for other costs such as childcare. For 16% of these campaigns it was noted that the financial hardship arose because of self-employment status. Parents of sick children experiencing financial hardship represented 34% of these 92 campaigns.

What potential gaps in the National Health Services (NHS) and social care may prompt people to seek medical fundraising online?

Cancer services

As noted, half of the reviewed campaigns requested funds for cancer care, a concern highlighted elsewhere.^{12,13} Our analysis found that related campaigns included both common (breast and bowel) and rarer cancers (e.g. brain/central nervous system and sarcomas), pointing to wider issues around cancer services in the UK.¹⁴ The share of campaigns devoted to patients with disclosed stage 4 cancer (32%) could indicate possible gaps particularly in end-of-life care. Our findings might reflect, in part, moves by affected individuals in terminal stages when there appear to be no more treatment options left within the NHS compared to the private sector in the UK or overseas, with crowdfunding providing a means to fund the latter.

Access to novel therapies

As a large number of crowdfunding recipients seek funds for treatment abroad (136 from the 400 we sampled), our study suggests that some patients may believe they have access to (better) care elsewhere, which makes them a subset of 'medical tourists'. A 2014 review of

literature focusing on people seeking treatment abroad found that most UK patients sought care for fertility, dentistry, cosmetic and bariatric surgeries.¹⁵ Our analysis and other studies showed that crowdfunding campaigns collected funds to access expensive stem cell therapies, cancer treatments and alternative therapies from private clinics worldwide.^{12,16,17} As such, medical tourism for patients who want to access novel and alternative therapies has become a new business, albeit some of relying on poor scientific foundations and requiring urgent regulation.^{12, 18}

Also one in five recipients sought funds for treatment in the UK private sector, mainly surgeries and procedures as well as cancer treatments showing that some therapies are accessible only privately which may foster inequalities.

Our findings, along with the literature suggest that with the flow of information available on the Internet, patients are increasingly aware of therapeutic advances but also may be victims of commercial traps and disinformation. Increasingly public authorities have to fight against health-related disinformation such as adverts for “miraculous” cures spreading online through narratives on social media, forums, blogs and crowdfunding campaigns.^{19,20} However, along with the expansion of new therapeutics, access is an important issue that needs a global response. Urgency to get access is even more important for patients with poor life prognosis and those with strong disabilities. With the rise of health globalisation, medical tourism is a growing phenomenon²¹ where the objective is not only to get a treatment faster or at a better price but to access what is not available within the domestic system.

Systemic issues across health and social care

The use of crowdfunding to support treatment in the private sector in the UK might point to some gaps in NHS health care, not only limited access to novel therapies and surgical

techniques, but also long waiting lists as noted in campaign narratives. Waiting lists remain a major challenge in the NHS, with for example standards for cancer care, requiring that at least 85% of patients should begin treatment within 62 days of an urgent referral from their GP, not met since 2013/14.²² Some campaigns also highlighted gaps in the range of services provided by the NHS, such as limited access to rehabilitation equipment and therapies, and available evidence has pointed to supply challenges within the NHS such as related facilities and workforce.²³

Our rapid review also found that nearly one in four campaigns sought support to help address the financial burden caused by ill health beyond medical treatment. This may point to important welfare gaps as loss of income during illness is not sufficiently compensated for considering expenses that arise from ill health (such as travel cost, equipment, childcare). In January 2018, the European Committee of Social Rights found that in the UK, statutory sick pay was inadequate and that in many cases, sick and unemployed people were receiving less than 40% of the UK median income (£152.22/week).²⁴

Dealing with biases in crowdfunding analysis

Analysing crowdfunding campaigns is subject to sampling bias, which arises primarily from the observation that not all existing campaigns are displayed on the platform; instead those that are shown are determined by algorithms set by the crowdfunding platform. The sample at any given point in time is most likely selected following an algorithm based on 'trending', success in raising funds and geographical location of the internet user. These algorithms are not in the public domain and we were unsuccessful in getting further information from GoFundMe UK.

Campaigns are shown in the order of the amount of funds raised. However, the success of a campaign depends on many factors, including the proportion between the amount of funds

requested and the amount collected, for how long the campaign was created for and the strength of campaigners' social network.

The most successful campaigns (in terms of amounts of funds raised) are therefore likely to be overrepresented, as will be those requesting larger sums of funding (for instance campaigns to fund cancer treatment.) The algorithm may also have overrepresented campaigns nearest from London (where the research was carried) even if little difference (-/+ 5%) has been observed between the research sample's geographical distribution and the UK population distribution.²⁵

These challenges are clearly something that needs to be addressed in future with more rigorous research.

Conclusion

Medical crowdfunding is a new but rapidly growing public health phenomenon. Ethical concerns have been raised that should encourage politics to work in the short term to regulate crowdfunding platforms to protect fundraisers and donors from fraudulent campaigns, vested interests, privacy breaches, adverts for therapies with poor scientific foundations and dubious private health care facilities. Our brief snapshot presents some key features of 400 medical fundraising campaigns identified from GoFundMe UK, highlighting some gaps in the UK health and social services that needs addressing to improve cancer services and treatment access as well as to better meet the demand. This review intends to show that medical crowdfunding research offers not only an innovative insight in population's unmet demands that could help improving national health and social services but also offers another perspective on medical tourism. For the longer-term, there is a clear need for more qualitative studies that would document the reasons why patients choose medical crowdfunding to finance their health care

or cope with financial burden, to investigate potential gaps in the system and the implications for health and equity.

References

- [1] Renwick MJ and Mossialos E. Crowdfunding our health: Economic risks and benefits. *Soc Sci Med* 2017; 191: 48-56.
- [2] Snyder J, Crooks VA, Mathers A et al. Appealing to the crowd: Ethical justifications in Canadian medical crowdfunding campaigns. *J Med Ethics* 2017; 43: 364–7.
- [3] Berliner LS and Kenworthy NJ. Producing a worthy illness: Personal crowdfunding amidst financial crisis. *Soc Sci Med* 2017; 187: 233-42.
- [4] Paulus TM and Roberts KR. Crowdfunding a “Real- life Superhero”: The construction of worthy bodies in medical campaign narratives. *Discourse, Context and Media J* 2017; 21: 64-72.
- [5] van Duynhoven A, Lee A, Michel R, et al. Spatially exploring the intersection of socioeconomic status and Canadian cancer-related medical crowdfunding campaigns. *BMJ Open* 2019; 9:e026365.
- [6] Moore B. Medical crowdfunding and the virtuous donor. *Bioethics* 2019; 33:238-244.
- [7] Dressler G and Kelly SA. Ethical implications of medical crowdfunding: the case of Charlie Gard. *J Med Ethics* 2018; 44: 453-7.
- [8] Snyder J, Mathers A and Crooks VA. Fund my treatment! A call for ethics-focused social science research into the use of crowdfunding for medical care. *Soc Sci Med* 2016; 169: 27-30.
- [9] Snyder J, Chow-White P, Crooks VA et al. Widening the gap: additional concerns with crowdfunding in health care. *Lancet Oncol* 2017; 18: e240.
- [10] GoFundMe United Kingdom. Pricing and fees, <https://uk.gofundme.com/pricing> (Accessed 20 May 2019)
- [11] GoFundMe United Kingdom. GoFundMe Help Centre. Common issues. Donors. Extra charge on statement. The GoFundMe Tip. <https://support.gofundme.com/hc/en-gb/articles/115015446027-Extra-Charge-on-Statement> (Accessed 20 May 2019)
- [12] Newman M. Is cancer fundraising fuelling quackery? *BMJ* 2018; 362.
- [13] The Lancet Oncology. Mind the gap: charity and crowdfunding in health care. *Lancet Oncol* 2017; 18: 269.
- [14] Office for National Statistics website. National cancer registration statistics, England 2016. Registration. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/final2016> (Accessed 2 July 2018).
- [15] Hanefeld J, Smith R, Horsfall D, et al. What do we know about medical tourism? A review of the literature with discussion of its implications for the UK National Health Service as an example of a public health care system. *J Travel Med* 2014; 21: 410-7.

- [16] Snyder J, Turner L and Crooks VA. Crowdfunding for unproven stem cell–based interventions. *JAMA* 2018; 319: 1935-6.
- [17] Vox F, Folkers KM, Turi A, et al. Medical Crowdfunding for Scientifically Unsupported or Potentially Dangerous Treatments. *JAMA*. 2018; 320:1705-1706.
- [18] Wagstaff A. Medical tourism: a passport to timely high-quality cancer care? Systems and services. *Cancer World* July-August 2015; 32-38.
https://cancerworld.net/wpcontent/uploads/2016/12/2015_pagina_32-38_SystemsServices.pdf (Accessed 5 November 2019)
- [19] Hesse BW, Nelson DE, Kreps GL, et al. Trust and Sources of Health Information: The Impact of the Internet and Its Implications for Health Care Providers: Findings From the First Health Information National Trends Survey. *Arch Intern Med*. 2005;165:2618–2624.
- [20] West H. Online Cancer Information and Patient Groups. *JAMA Oncol*. Published online July 03, 2019; 5:1376.
- [21] Foley BM, Haglin JM, Tanzer JR, et al. Patient care without borders: a systematic review of medical and surgical tourism. *Journal of Travel Medicine* 2019; 26:taz049.
- [22] Anandaciva S and Thompson J. What is happening to waiting times in the NHS? The King’s Fund, <https://www.kingsfund.org.uk/publications/articles/nhs-waiting-times> (8 November 2017, accessed 30 August 2018)
- [23] McCullough AL, Haycock JC, Forward DP et al. II. Major trauma networks in England. *Br J Anaesth* 2014; 113: 202-6.
- [24] European Committee of Social Rights. Conclusions XXI-2. Article 12-1. Right to social security. United Kingdom, <http://hudoc.esc.coe.int/eng?i=XXI-2/def/GBR/12/1/EN> (8 December 2017, accessed 23 July 2018)
- [25] Office for National Statistics. *Population estimates 2016-2017*. www.ons.gov.uk