# Recruiting and retaining volunteer stool donors 

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## Overview

Treatment for patients with recurrent Clostridioides difficile (C. difficile) using Faecal Microbiota Transplantation (FMT) of donated stool has demonstrated high success with up to a $90 \%$ cure rate for patients. Traditionally, stool has been donated by a person identified by and known to the patient. However, stool banks which rely on volunteer donors unknown to the patient are more advantageous because they adopt more stringent screening and minimise delays in patient's access to treatment. Thousands of patients globally would benefit from FMT, however, the number of eligible donors do not meet demand. Reports from clinical trials and clinics indicate that recruitment of volunteer stool donors is challenging, with high costs for donor screening, and difficulty retaining donors.

The success of FMT and further expansion of work in the area depends on a reliable, continuous supply of healthy volunteer stool donors from targeted populations (e.g., blood donors), community cohorts, and/or patients. Thus donor recruitment, retention, and the donor's relationship with the service is critical. Motives, experiences, responses to deferral, facilitators and barriers to stool donation are key aspects likely impacting donor supply.

## Rapid and brief reviews

We undertook a rapid review of available FMT donor research focused on universal stool donors (not known to the patient) to identify information about their recruitment and retention. Searches were conducted in September 2019 via Web of Science and Google Scholar, and cited reference searches, and identified 34 articles. In addition, and with the aim of drawing insights to inform stool donor recruitment, we undertook brief reviews of complementary research areas that examined patient, health professional, community, or volunteer perspectives towards procedures or tests involving faecal matter, as well as biobanking and clinical trial participation (51 articles).

## Results

## Volunteer stool donor research

Few studies have volunteer stool donors as a central focus. Gaps in the literature include understanding the characteristics of first-time and repeat donors, their motives, retention, and also reasons for deferral of repeat donors. Facilitators and barriers to stool donation are not well described. Thus, findings in this area are preliminary.

- Stool donors are most often male and, on average, aged 28-40 years.
- Increased willingness to volunteer was associated with motives commonly found in blood donation settings such as altruism, knowledge and positive attitudes, and financial or health information incentives; as well as characteristics such as being male and a blood donor.
- Logistics, particularly screening requirements, frequency of donation, and duration of the collection period, were key barriers to donation. Female blood donors were more likely to decline because they viewed stool donation as unappealing.
- Donor recruitment overall was noted as challenging and costly. Up to $75 \%$ of potential donors were lost at pre-screen and/or completion of clinical interviews. Common reasons for early exclusion were medication use (e.g., antibiotics), high BMI and logistics.
- Of those who passed pre-screening, in some studies over half were lost to follow-up and did not attend clinical interview. After screening, potential donors were excluded most commonly for B. hominis, D. fragilis, or H. pylori, as well as incidental detection of rotavirus and C. difficile.
- Acceptance rates of community donors screened and enrolled in programs ranged from 1.6\% to 31.8\%. In Australia specifically, acceptance rates ranged from 10\% to 32\%. Acceptance rates for Danish blood donors ranged from $23 \%$ to $62 \%$.


## FMT attitude, biobanking, clinical trial, and colorectal cancer screening research

- There was no clear pattern regarding characteristics of people who were more or less likely to view FMT positively or participate in biobanking, clinical trials, or screening. Although gender was a key influence, there was no consensus regarding its impact. Women viewed handling stools as more displeasing than men, but were more likely to undertake colorectal cancer screening than men.
- Across all areas, lack of awareness or knowledge was associated with less positive attitudes and/or less willingness to participate. In relation to FMT particularly, there were concerns about disease transmission, adequate screening of donors, and the need for clarity about what makes someone a 'healthy donor'. Concerns in clinical trial and biobanking sectors centred on breaches of confidentiality, privacy, and risks that impacted patient's health, insurance, or access to care. Misuse of information and samples for purposes other than those agreed to by participants were also barriers to participation.
- A positive endorsement from a health professional such as a physician or GP dispelled negative perspectives of FMT, and increased willingness and participation in biobanking, clinical trials and screening.
- Advancing medical or scientific research, and helping others through these advances, were primary motivators across FMT, biobanking and clinical trial contexts. Benefits to self, such as improved health, personalised genetic/health information, and gaining access to additional care, was also a central motivator. Financial incentives were important but not sufficient to encourage clinical trial and biobanking participation.
- Facilitators of positive attitudes to FMT or participation in biobanking, clinical trials, or screening included the need for convenience and flexibility (e.g., scheduling, contributing additional samples during usual appointment, reduced frequency of participation) and enhanced capabilities (easy to follow instructions and collect a stool sample).
- Adopting a personalised approach also improved participation by demonstrating the relevance, purpose, and value (how and who it helps) of FMT and donating for research purposes, and increased acceptability of treatment and collection involving faecal matter. Personalised invitation letters or in-person requests, and personalised genetic or health information incentives, improved recruitment.
- Participants were less willing to contribute stool than blood or saliva, and disgust ('yuck' factor) was prominent. Information about microbiome research and therapies (FMT) that used explicit language and reference to disgusting stimuli, and had a human focus, increased disgust, and subsequent views on regulation and perceived risk.
- Contrary to the view of blood and organ donation as a 'gift', donation of biospecimens such as stool for FMT, biobanking, and clinical trials were not viewed as 'gifts' and did not have the same value attached as blood or organs. The perceived value of biospecimens lay in the information derived from these samples and how this information could then be used to advance science/medicine or help others.


## Recommendations

1. Target males and blood donors as potential stool donors. This recommendation is preliminary, given there has not been an examination of gender differences in attitudes or acceptance rates of female, as compared to male, FMT donors.
2. Emphasise the value of participation and the information gained from stool donation when recruiting donors, rather than highlighting stool donation as a 'gift'.
3. Use patient stories to overcome the 'yuck' factor, increase acceptability, and encourage participation. Consider also using a medical practitioner to tell an FMT patient success story to increase perceived legitimacy and acceptance of stool donation.
4. Offer incentives that are informational, particularly information that relates directly to the donor (e.g., genetic or health information), rather than financial.
5. For blood donors who are asked to donate stool for patients or research purposes: personalise the request; share patient success stories and stories of patients who need FMT so donors understand the relevance and value of stool donation and it connects with their original motivation to donate blood to help patients; increase convenience by incorporating screening and stool donation into their usual blood donation; emphasise that for a little extra effort their donation provides even more benefit; and reassure donors about privacy and confidentiality and use of information and samples.
6. Most potential donors are lost at pre-screen and this stage needs to be time- and costeffective. Strategies could include online pre-screening (akin to blood donation), making the logistics of stool donation transparent prior to screening so potential donors have a good understanding of what is required, how often, and for how long, and including BMI criteria as part of pre-screening (instead of at clinical interview).
7. Reduce delays between pre-screening and follow-up, and increase convenience and ease of participation by having a single in-person interview in which clinical assessments are made and the initial stool donation takes place to reduce loss of donors who have successfully completed pre-screening.
8. Create a program of research on donor recruitment and retention in order to support a reliable supply of stool donors for newly established and existing FMT programs and clinical trials.

## Citation

Hyde MK, Masser BM. (2019). Recruiting and retaining volunteer stool donors. Donor Research Network. Available: https://research.psy.uq.edu.au/dorn/stool-donors/

If you would like a copy of the full report, please contact the authors at m.hyde@uq.edu.au and b.masser@psy.uq.edu.au

