

Using **social media** to recruit participants in cancer care research: **challenges & opportunities**

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The problem:

- ✓ It is difficult to identify, recruit & retain seriously ill patients in research¹.
- ✓ However, research has shown that up to **92% would be happy to be asked** to participate².
- ✓ Are we missing important data because we cannot reach these populations?
- ✓ **Social media** is rapidly arising as a new way to recruit.

What is social media?

It is not “just” Facebook or LinkedIn. The use of SM in health care is embedded in the **eHealth** paradigm: proactive, engaged patients and a holistic approach: biopsychosocial model.

It is widely used in industry & communications. More and more studies are using it to recruit in healthcare research³.

Challenges



- **Digital breach**: whilst the use of the internet and SM has become mainstream in the Western world during the last decade, there are still millions of people that cannot access this technology. This can be due to lack of internet connection or equipment, or to a lack of skills.
- **Sample bias**: there may be concerns whether participants recruited via SM are different from those recruited via traditional methods. Some studies have suggested that SM users are younger and from higher socio-economic class in comparison to non-SM users⁴.
- **Screening**: recruitment in SM is based on a self-referral process and its success depends on the participants' accurate understanding of the clinical information given to them by the health care team.
- **Ownership of content**: legal issues must be taken into account, since data posted in SM is stored on private companies' servers. This is especially relevant for Facebook and Twitter. Users are often unaware of data protection policies.

Opportunities



- **Wider reach**: SM is not limited to time and space. Potential participants have access to the information 24/7, anywhere with an internet connection.
- **Direct access**: SM allows direct interaction with the user, minimising the involvement of “gatekeepers”.
- **Readiness of the data**: in some cases, data might be already available (e.g. analysis of videos posted in YouTube about a specific clinical condition).
- **Empowered participants**: it allows the potential participants to decide by themselves without the need for a mediator. In this sense, SM empowers participants by giving them more control and possibly involvement in research.
- **Financial**: recruitment using SM only needs the cost of Internet access, which makes it an affordable tool. In some cases, paid advertisement may be added in order to maximise recruitment.

Implications for research:

- **Opportunities** provided by this method of recruitment should not be overlooked, as it can be used flexibly alongside traditional methods, depending on the needs of each research project.
- **Methodological**: the characteristics of participants recruited by traditional methods versus SM may impact the analysis stage. The analysis plan needs further consideration and decisions need to be made whether data obtained via these two methods is analysed together or separate.
- **Guidelines** are needed in order to ensure that the well-being of the participants is guaranteed, just like we do when using traditional recruitment methods.

Implications for clinical practice:

- **eHealth** is part of a paradigm shift, where patients have become proactive and engaged.
- **Clinicians** need to be mindful of the changing identity of patients, which in turn may have an impact on the clinician-patient relationship.

