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The INPUT[1] survey of persons participating in clinical studies[2]

The survey in brief

and

a summary of its origins, process and findings

[1] From the German '**In**volvieren von **P**atient/innen **U**nd **T**eilnehmenden' ('Involvement of Patients and Participants')

[2] In the Human Research Act and the ordinances thereon, the term 'clinical trials' is used. Within the context of this survey, the terms 'clinical trials' and 'clinical studies' are regarded as synonyms. Over the course of the corresponding project, in all texts intended for patients and the public, the generally more understandable term 'clinical studies' has been used. Since this final report is also intended for a public audience, the term 'clinical studies' (and not 'clinical trials') has also been used.

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The survey in brief

The INPUT survey investigated how persons who were participating in clinical studies in Switzerland would describe their experience thereof.

Over 230 persons from all over Switzerland who were participating in such clinical studies took part in the INPUT survey, responding to questions about their motivation for doing so and the information and support they had received in connection therewith.

Most of the respondents had learned of the possibility of participating in a clinical study from medical professionals: only a few respondents had actively sought out such studies themselves or had been aware of patient registries.

The main motive among respondents for participating in their clinical study was the desire to contribute to medical research and/or to help others. The prospect of possible personal treatment benefits, of more intensified medical care and/or of additional support had been further motivations for respondents to participate in the clinical studies concerned.

Almost all survey respondents felt that they had been adequately informed about the clinical study they were participating in, with an in-person advance briefing to this end considered particularly important. Respondents also felt well able to understand the written information they had received.

Some uncertainty was expressed by respondents over some specific technical study issues such as incidental findings or the provisions regarding any damages claims. But most respondents felt secure and well cared for during their clinical study to date. Many of them had needed little time to decide to take part. And the majority of respondents wished their study's results to be both publicly accessible and also understandable to non-medical professionals.

A large number of the survey's respondents said that they would be willing to participate in a clinical study again and/or would recommend such participation to others.

All the survey's respondents were currently taking part in a clinical study. In view of this, the survey's results may be somewhat skewed in favour of contented and trusting participants, and more critical voices may be underrepresented.

All in all, the survey's results suggest confidence in the research being conducted, but show potential for improvement, too, in people's ability to find out about opportunities to participate in clinical studies, and also in the accessibility of study results.

A summary of the survey's origins, processes and findings

With the entry into effect of the Human Research Act (HRA, SR 810.30) on 1 January 2014, the legal framework was established to protect the dignity, privacy and health of persons involved in human research. The Federal Office of Public Health (FOPH) is tasked with evaluating the effectiveness of this legislation. Within the context thereof, the Department of Clinical Research at the University of Basel was commissioned to conduct a survey of persons currently participating in clinical studies.

The resulting INPUT survey was intended to systematically determine its respondents' views on and experiences of various aspects of their clinical study participation – information, explanations, consent, care, motivations, protections and results communication – with a view to proposing any improvements needed to the same in the implementation of the HRA or to making any amendments required to the existing legal provisions.

To conduct the survey, 872 current clinical studies were identified from the Swiss Ethics Committees' Registry of All Projects in Switzerland (RAPS). With the support of the corresponding sponsors[3], 65 clinical studies with 88 study centres nationwide could then be enlisted to distribute the invitations to participate in the INPUT survey.

The survey respondents from the clinical studies selected were able to provide their responses either online or in paper form. A total of 236 evaluable responses were received. The average age of the respondents was 60 (with an age range of between 23 and 92). Some 59% were male and 36% female, with no non-binary respondents. The respondents came from 21 different cantons, with German speakers most strongly represented at 75%.

When respondents were asked how they had first been alerted to the possibility of participating in a clinical study, contacts with medical professionals or healthcare institutions was the source most cited. Very few respondents (3%) had actively sought out clinical studies themselves, and few (12%) were aware of patient registries.

When respondents were asked their reasons for participating in their clinical study, the main motives cited were altruistic motivations (helping others [72%] and/or contributing to medical research [67%]), followed by hoped-for personal benefit (such as additional examinations and tests [31%] and more intensified care [20%]). Further motives occasionally mentioned by respondents included family factors, curiosity and trust in the study centre concerned.

The majority of respondents felt well informed about their clinical study, with the written information on their participation regarded as both understandable (by 93%) and helpful (by 89%).

More than a third (36%) of respondents would welcome the use of additional media to support study-specific education. Most of them felt that the amount of written information provided was appropriate, though some (15%) considered it too long. Of particular importance to respondents in information terms were spoken explanations (cited by 92%), details of the time and energy involved (89%) and information on how study data would be used (84%), their right to withdraw (83%) and the voluntary nature of their participation (82%). No topics were cited as not being covered by the information they received. There was, however, felt to be inadequate clarity on such issues as the handling of incidental findings and the provisions regarding any damages claims, both of which 74% of respondents described as important (with a 'no response' rate of between 16% and 21%).

[3] Defined under the Ordinance on Clinical Trials of 20 September 2013 (as at 1 March 2025) as a person or institution domiciled or represented in Switzerland that is responsible in Switzerland for the conducting of a clinical trial, and in particular for its initiation, management or financing.

When asked how promptly they had decided to take part in their clinical study after being informed about it, a majority of respondents reported doing so within 24 hours (and 62% immediately). Only few respondents needed substantially more time.

Most respondents (86% to 89%) felt secure, taken seriously and well looked after during their study participation, and were satisfied with the information provided on the time and energy commitment involved, the examinations entailed and any inconveniences or discomfort they should expect.

The majority of respondents (86%) agreed that the new legislation achieves its purpose, though a number of them declined to answer this survey question.

A majority of respondents (68%) felt that their study's results should be made available in language that is also understandable to non-medical professionals, while 65% felt that such results should also be publicly accessible. Only just under a third (31%) of respondents felt that it would suffice to communicate the results concerned solely to medical professionals.

Most respondents (82%) said that they would be willing to take part in another clinical study, while a similarly high 78% would recommend such participation to friends. These results suggest a general confidence and trust in the kind of clinical research that is being conducted by the teams involved in the studies surveyed in accordance with the relevant legal parameters.

Since the INPUT project puts a particular focus on persons who are currently participating in clinical studies, it was considered especially important to involve appropriately experienced parties in the project from its early planning phase. These endeavours to pay due and full regard to the participants' perspective (through patient and public involvement or PPI) were also supported by the FOPH as early as the conceptual phase. As a result, a number of requests for modifications to the original concept (such as the addition of a paper response option) could be integrated into the final INPUT survey.

One particular challenge was posed by the need to invite potential survey participants to take part in the survey without recording their contact details via direct contact with their clinical study teams. Some of the sponsors involved (or their representatives) had reservations about further burdening the study teams and participants with the additional work entailed. And the primary contacts with the study teams had to be via the sponsors, for data protection reasons.

In interpreting the survey results, due regard must be paid to the fact that all the persons surveyed were actively participating in clinical studies at the time the survey was conducted, and can thus be assumed to have had a certain amount of confidence in and satisfaction with the processes involved in such clinical studies and participation therein. It is possible, therefore, that less satisfied clinical study participants are underrepresented in the survey responses.

To our knowledge, the INPUT survey is the first departmental research project to specifically survey the group of persons most affected by human research: patients (in the form of clinical study participants).

The survey's responses suggest that few such patients will actively seek out opportunities to participate in clinical studies, and also that the existence of patient registries remains largely unknown.

The duties to inform prescribed by law (i.e. adequate clarification in advance on study participation) were considered to be fulfilled among survey respondents. But there is a clear demand for clinical study results to be made available in language that can also be understood by non-medical professionals.

In the view of the majority of the clinical study participants who took part in the INPUT survey, the relevant legal provisions are achieving their purpose.