

Supplementary Table 1. Status at follow-up in 2018-19 of the 1178 participants of the 1985 Swiss AS Family Study and response rate

Category	Number
Known to be deceased (probands 123; FDR 39)	162
Agreed to participate (probands 125; FDR 360)	485
	647 (54.9%)
<i>Missings</i>	
Agreed to participate; questionnaire not returned	24
Declined participation	23
No reply on invitational letter <i>or</i> incorrect address	232
Current address unknown	169
Living abroad, address unknown	72
Otherwise (address blocked; non-german speaking)	11
	531 (45.1%)
Total	1178 (100%)

Number of invitational letters sent: 791; response rate: 485/791 (61.3%)

Number participants follow-up study/participants baseline study: 485/1178 (41.6%)

## Supplementary Table 2.

## Lessons learned – Swiss AS Family study 1985- 2019

*Changes over time*

## People

Study participants marry, divorce, change names, move and die

Lesson: use national IDs for tracking purposes

## City &amp; villages administrations

Boundaries, community names and archives change

## Imaging technology changes over time

Physical pelvic radiographs outdated, new technologies (MRI) emerged

## Storage of data and forms

From mainframe computer to PC

Lesson: transfer data on time to actual standard storage technology

Paper copies fade away

Lesson: store data on more than one location. Make backups

## Motivation

People may forget having participated

Lesson: send periodically newsletter

Challenge: keep track of postal and email addresses

(Note: email not yet available in 1985)

