Attendance to follow-up care in survivors of adolescent and young adult cancer: application of the theory of planned behaviour

Katharina Roser (PhD) a, Julia Baenziger (MSc) a, Luzius Mader (MSc) a, Salome Christen (MA) a, Silvia Dehler (Dr.med.) b,c, and Gisela Michel (PhD) a,d,*

a University of Lucerne, Frohburgstrasse 3, PO Box 4466, 6002 Lucerne, Switzerland; katharina.roser@unilu.ch, julia.baenziger@unilu.ch, luzius.mader@unilu.ch, salome.christen@unilu.ch, gisela.michel@unilu.ch
b Cancer Registry Zurich and Zug, Institute of Surgical Pathology, University Hospital Zurich and Epidemiology, Biostatistics and Prevention Institute, University Zurich, Vogelsangstrasse 10, 8091 Zurich, Switzerland; silvia.dehler@ag.ch
c Departement Gesundheit und Soziales, Abteilung Gesundheit, Bachstrasse 15, 5001 Aarau, Switzerland; silvia.dehler@ag.ch
d Institute of Social and Preventive Medicine, University of Bern, Finkenhubelweg 11, 3012 Bern, Switzerland; gisela.michel@unilu.ch
* Corresponding author

Corresponding author
Gisela Michel
Department of Health Sciences and Health Policy
University of Lucerne
Frohburgstrasse 3
PO Box 4466
6002 Lucerne
Switzerland.
Phone: +41 41 2295955
Fax: +41 41 2295635
Email: gisela.michel@unilu.ch

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Abstract

Purpose

The aim was to study follow-up care attendance in AYA cancer survivors to investigate: i) correlates of the intention to attend follow-up care, and ii) whether the intention is associated with the actual attendance, applying the theory of planned behaviour (TPB).

Methods

We conducted a questionnaire survey in AYA cancer survivors diagnosed 1990-2005 at age 16-25 years, registered in the Cancer Registry Zurich and Zug, Switzerland, who had survived at least five years. Structural equation modelling was applied to investigate TPB-related correlates (attitudes, subjective norms, and perceived behavioural control) of intention to attend follow-up care. Logistic regression analysis was used to study the association between intention and actual attendance.

Results

We included 160 AYA cancer survivors in the study (mean age at study: 34.0 years, mean age at diagnosis: 21.6 years, 98 (61.3%) male). Positive attitudes towards follow-up care (Coeff.=0.32, 95%CI:0.05-0.60) and supportive subjective norms (Coeff.=0.59, 95%CI:0.41-0.78) were associated with higher intention to attend follow-up care. Perceived behavioural control was not associated with intention to attend (Coeff.=-0.13, 95%CI:-0.36-0.10), but with actual attendance (OR=4.55, 95% CI:1.83-11.31). Higher intention was associated with actual follow-up care attendance (OR=14.29, 95%CI:5.80-35.21).

Conclusion

Positive attitudes and supportive social norms were associated with higher intention to attend follow-up care, and higher intention was associated with actual follow-up care attendance. Increasing awareness of the importance and benefits of follow-up care among survivors but also family, friends and health care professionals may help to increase follow-up care attendance among AYA cancer survivors.
Introduction

Five-year survival of European adolescent and young adult (AYA) cancer patients has increased remarkably and reached 87% for patients diagnosed between 1995 and 2002. However, late effects of cancer and its treatment are common and include various medical conditions, decreased mental health and health-related quality of life, and psychosocial problems. Attendance to follow-up care is important to detect late effects early and to treat and support survivors accordingly. Consequently, it is important to investigate correlates of follow-up care attendance among AYA cancer survivors.

Research showed that female and older survivors were more likely to attend recommended follow-up care, and attendance rates decreased with more time after diagnosis. More than five years after diagnosis, 40% of survivors reported not having attended a routine medical visit during the last year. Furthermore, lower quality of life and more health problems were associated with more medical out-patient visits in long-term survivors indicating that there might also be a link to follow-up care attendance.

Perceived barriers to attend medical care included lack of insurance, high costs, no guidance from the oncologist, no perceived need for follow-up care, not enough information regarding follow-up care, conflict with other responsibilities such as family and work, fear of new cancer, and avoidance of care related to the former cancer disease.

Knowledge on cognitive correlates of follow-up attendance is still lacking. To address this gap, we applied the theory of planned behaviour (TPB) to investigate cognitive correlates of follow-up care attendance in a population-based sample of AYA cancer survivors in Switzerland. The TPB suggests that the intention to perform a behaviour predicts the actual behaviour. The intention itself is predicted by three constructs: attitudes towards the behaviour (referred to as attitude), subjective norm (norm) and perceived behavioural control (control). Additionally to the intention, the actual behaviour is predicted by control. Attitude refers to a person’s favourable or unfavourable opinions about the behaviour of interest, norm refers to perceived expectations among the social environment to perform the behaviour, and control refers to the perceived easiness or difficulty to perform the behaviour. Generally, more positive attitudes and norms, and greater control are expected to be associated with a higher intention to perform the behaviour, and a higher likelihood that the behaviour is actually performed. Survivors’ positive attitudes towards follow-up care, the perception that family, friends and health professionals support or expect their attendance, and the perceived easiness to attend care are thus expected to increase the intention of survivors to attend follow-up care.

The aim of our study was to investigate whether the TPB helps predicting follow-up care attendance in Swiss AYA cancer survivors. Specifically, we aimed at investigating: i) TPB-related correlates of the intention to attend follow-up care, and ii) whether the intention is associated with the actual attendance.

Methods

Study participants

Eligible survivors had been diagnosed with cancer in the Canton of Zurich, Switzerland, between 1990 and 2005, aged 16-25 years at diagnosis, registered in the Cancer Registry
Zurich and Zug, Switzerland, and survived ≥5 years after diagnosis. Cancer diagnoses were restricted to leukaemia, germ cell tumour, lymphoma, central nervous system tumour (CNS), neuroblastoma, renal, hepatic and bone tumour, and soft tissue sarcoma to enable comparison with a cohort of Swiss childhood cancer survivors. 17,18

**Procedure**

A mailed questionnaire survey was conducted between August 2010 and January 2012. Addresses of eligible survivors were available from the registry. After four weeks, a reminder letter was sent to non-responders. The study was approved by the Cantonal Ethics Committee of Zurich, and informed consent was obtained from all participants.

**Assessment of correlates, intention and attendance**

Correlates (attitude, norm, and control) and intention were measured by indicator variables which were assessed using 7-point Likert scales (Table S1 in Supplementary Material). Questions were developed according to the TPB manual by Francis et al. (2004). 19 Attitude was measured by asking for the agreement with five items: ‘I find regular follow-up unnecessary – meaningful; bad – good; unpleasant – pleasant; boring – interesting’, and ‘To me, detecting and treating possible late effects of my cancer is unimportant – important’. Norm was assessed asking for the degree of agreement with the following items: ‘Most people that are important to me think I should attend to follow-up care.’; ‘It is expected from me that I attend to follow-up care regularly.’ Control was measured using three items: ‘For me, attending regular follow-up is complicated – easy; stressful – not at all stressful’, and the degree of agreement with ‘It is foremost in my hands whether I regularly attend follow-up or not’. Finally, intention was assessed by asking for the degree of agreement with two items: ‘I intend to attend follow-up next year.’ and ‘It is likely that I will attend follow-up within the next year’. To assess follow-up care attendance, survivors were asked whether they still attended follow-up care. We coded those who attended regular or irregular follow-up as attenders, and those who rarely or never visited their former treating doctor as non-attenders 11 (Table S1 in Supplementary Material).

**Covariates**

**Socio-demographic characteristics**

Sex was assessed in the questionnaire and obtained from the registry for non-participants. Age at study, educational achievement, employment status, partnership, and migration background were assessed in the questionnaire. Educational achievement of survivors was coded as compulsory schooling, vocational training, upper secondary education, and university degree. 20 Survivors were classified as having a migration background if they were not Swiss citizen, had moved to Switzerland after birth or if they were not Swiss citizen since birth.

**Clinical characteristics**

Late effects, cancer relapse and second malignancies were assessed in the questionnaire (yes/no). Furthermore, survivors were asked if they were afraid that late effects are detected when attending follow-up care (7-point Likert scale).
Clinical information from the registry

Information on diagnosis (classified according to the International Classification of Childhood Cancer, third edition (ICCC-3) \(^{21}\)), age at diagnosis, treatment, and time since diagnosis were extracted from the registry. Treatment was hierarchically coded as surgery only, chemotherapy (may have had surgery), and radiotherapy (may have had surgery and/or chemotherapy).

Statistical analysis

Descriptive statistics, chi-square tests and t-tests were used to compare participants and non-participants.

Aim 1: Structural equation modelling (SEM)

We used structural equation modelling (SEM) to investigate correlates of the intention to attend follow-up care. SEM allows investigating associations between latent (unmeasured) factors based on measured indicator variables. A two-step approach to SEM was used. \(^{22}\) First, an adequate measurement model was built; then the TPB-based structural model was added. The final SEM consisted of two parts: a measurement model depicting the relationships between indicators (indicator variables from the questionnaire) and latent factors (correlates and intention), and a structural model representing the paths between latent factors (Figure 1).

The measurement model consisted of four parts representing the four latent factors attitude, norm, control, and intention measured by indicators. Higher scores indicate more positive attitude, more supportive norm, higher control, and higher intention. Cronbach’s alpha measuring internal consistency was calculated for the four latent factors. Principal component factor analysis (PCFA) was applied for each factor separately to test whether the indicators loaded on one factor each. A confirmatory factor analysis (CFA) was conducted for the four factors together. Modification indices (MI) based on CFA and theoretical justification were used to modify the measurement model. The structural model consisted of three paths pointing from the correlates to intention (Figure 1).

Maximum likelihood estimation taking into account all available information in the data in the presence of missing values was applied. Thus, no imputation of missing values was necessary to run the SEM. To estimate the precision of the model parameters the robust Huber/White/sandwich estimator was used.

To assess goodness of fit the following measures were used: \(X^2\) (chi-squared) test statistic, root-mean-square error of approximation (RMSEA) with corresponding 90% confidence interval, and the standardized root-mean-square residual (SRMR) for overall model fit, and Comparative Fit Index (CFI) and Tucker-Lewis Index (TLI) for the comparison with baseline models. \(^{23}\) For programming reasons the goodness of fit measures had to be obtained without applying the robust standard error estimation.
Aim 2: Logistic regression analysis

We applied multivariable logistic regression analysis to investigate the association between intention and actual attendance to follow-up care (Figure 1). Control and intention were included in the analysis as factor scores derived from the measured indicators. For the calculation of the factor scores, missing values in indicators were imputed with the mean of the available indicators of control or intention, respectively.

Covariates

Socio-demographic and clinical covariates were included in the SEM and multivariable logistic regression analyses if they were associated with intention or attendance in univariate regression analyses at p<0.05 level (Table S4 in Supplementary Material). Consequently, both analyses were adjusted for age at study, time since diagnosis, late effects, relapse, new cancer, and fear of detecting late effects during follow-up care (Table S4 in Supplementary Material). Additionally, they were adjusted for sex. Age at study and time since diagnosis were included as continuous variables.

Statistical analyses were carried out using Stata version 14.2 (StataCorp LP, College Station, Texas, USA).

Results

Study participants

Among 469 cancer survivors eligible for the study, 389 (82.9%) could be contacted. Of those, 160 (41.1%) returned the questionnaire and were included in the analysis.

The mean age of the participants was 34.0 years and 98 (61.3%) were males. Their mean age at diagnosis was 21.6 years. The most common diagnosis among the participants was lymphoma (60, 37.5%), followed by germ cell tumours (46, 28.7%), CNS tumours (15, 9.4%) and soft tissue sarcomas (15, 9.4%). One third of the participating survivors was treated with surgery only (57, 35.6%), 36 (22.5) with chemotherapy and 41 (25.6%) with radiotherapy. About a quarter of AYA cancer survivors (44, 27.5%) reported to suffer from late effects.

Participants and non-participants were similar regarding sex, age at study, diagnosis, cancer treatment, age at diagnosis and time since diagnosis (Table 1). More than half of the survivors (n=92; 57.5%) reported to attend follow-up care.

Structural equation modelling

Internal consistency measured by Cronbach’s alpha was $\alpha=0.80$ for attitude, $\alpha=0.88$ for norm, $\alpha=0.99$ for intention, and $\alpha=0.43$ for control. According to the PCFA, the indicators for attitude, norm and intention loaded on one factor each (Table S2 in Supplementary Material). The indicators for control loaded on two factors, one for the indicators C1 and C2, and another one for indicator C3. Therefore, indicator C3 was excluded for further analyses. Internal consistency was $\alpha=0.71$ for indicators C1 and C2 of control.

The MI of the CFA proposed to free the covariances between two pairs of attitude indicators (indicators A1 and A2: MI=35.5; indicators A3 and A4: MI=29.3). Since these two indicators
were also related from a theoretical point of view, the covariances were freed. The loadings of the indicators on the factors were strong and statistically significant (Tables S3, S4 in Supplementary Material).

The results were similar with and without robust standard error estimation with slightly larger confidence intervals without the robust estimation. The CFA showed acceptable to good model fit (23) (Tables S3, S4 in Supplementary Material).

**Aim 1: Correlates of intention**

Positive attitude towards follow-up care (Coeff.=0.32, 95%CI: 0.05-0.60) and higher supportive norm (Coeff.=0.59, 95%CI: 0.41-0.78) were associated with higher intention to attend follow-up care (Table 2, Figure 1). Control was not associated with intention (Coeff.=-0.13, 95%CI:-0.36-0.10). Having had a relapse was associated with higher intention. The model explained 73.8% of the variance in intention (Table 2). The results were similar with and without robust standard error estimation. The model showed acceptable to good model fit. 23

**Aim 2: Intention and actual attendance**

Both, higher intention to attend follow-up care (OR=13.77, 95% CI: 5.58-33.95) and higher control (OR=6.30, 95% CI: 2.26-17.53) were associated with actual attendance (Table 3, Figure 1). Having late effects, having had a relapse and higher fear of detecting late effects during follow-up care were associated with attendance to follow-up care (Table 3).

**Discussion**

We found that positive attitudes towards follow-up care and the perception that the social environment expects the survivor to attend follow-up care (supportive norms) were associated with higher intention to attend follow-up care in Swiss AYA cancer survivors. Survivors with a higher intention to attend follow-up care and those who perceived it to be easier to attend (higher perceived control) were more likely to actually attend follow-up care.

Facilitating and promoting positive attitudes towards follow-up care might help to increase follow-up care attendance in AYA cancer survivors. With more time passed since diagnosis, attendance rates to follow-up care decrease, 11-14 and also attitudes towards follow-up care worsen. 4 Thus, it might be especially important to sustain and promote positive attitudes among long-term survivors. Also attitudes of health care professionals towards follow-up care might influence attitudes of survivors and thus follow-up care attendance: other studies found that reasons to not attend follow-up care were that survivors felt that health care professionals would not have enough time to provide care, 10 or that there was no guidance from their oncologist regarding follow-up care. 15 Thus, survivors but also health care professionals should be continuously informed about the importance of follow-up care. 13, 15 This might be achieved by implementing survivorship care plans, 24 as there seems to be a lack of age-appropriate information for AYA cancer survivors. 4, 25-32

Supportive social norms might also increase follow-up care attendance. Although AYAs are mature, parents play an important role during but also after the end of treatment. 33 We found that expressing the importance of follow-up and the expectation that survivors attend
follow-up increased the intention to attend follow-up. This is in line with a reason for not attending medical out-patient visits found in another study: non-attending survivors perceived that health care professionals felt survivors would not need follow-up care. 13 Thus, families and friends of survivors and health care professionals should be advised about their role in supporting survivors to attend follow-up care what is expressing the importance and expectation of attendance.

We did not find perceived control being associated with the intention to attend follow-up but with actual attendance. Survivors generally reported finding it easy to attend follow-up care (Table S1 in Supplementary Material). These results might mirror the fact that due to the small country size, well-maintained public transport system and mandatory health insurance in Switzerland it is straightforward to attend follow-up care if a survivor is willing to do so. Thus, logistics, health care system or insurance related barriers to attend medical care identified in other studies 13-15 might not hold for Switzerland. Perceived control might still be increased by providing survivors with guidance regarding follow-up care by for instance implementing survivorship care plans. 24 Survivorship care plans might help empowering survivors to take responsibility for their health, for instance by attending regular follow-up care. Furthermore, high perceived control is only possible if follow-up care is available and ideally tailored to the needs of AYA cancer survivors. In other studies, survivors reported the need for age-appropriate follow-up care that is accessible, affordable and flexible to be compatible with work and family. 4, 13, 25, 34 Regarding organization of follow-up, care led by an oncologist in an adult hospital was preferred, 11, 35 a multidisciplinary team involved was favoured as well. 11, 30, 33 Medical reasons for follow-up were rated higher than supportive reasons by both, survivors 11, 35 and health care professionals. 36 Thus, follow-up care should include the provision of diverse information including former cancer disease and treatment, 24, 32 and monitoring for late effects. But follow-up care should also include psycho-social support services outside the clinical setting, and cover aspects such as insurance or employment issues. 4, 35

The presence of late effects, having had a relapse, and higher fear of detecting late effects during follow-up were associated with actual attendance in our study. Suffering from late effects and relapse of cancer make it necessary to seek medical care. A main aim of follow-up care is to detect late effects. The fear of detecting late effects might thus be due to this awareness. On the other hand, survivors attending care might be more anxious in general, and have a higher need for monitoring their health. Our findings are in line with a study in Canada reporting that most common reasons for medical care visits in AYA cancer survivors were secondary neoplasms and other health-related symptoms. 12 In contrast, a study in the USA found the fear of new cancer being a barrier to attend follow-up care. 15 This contrast might be due to a culturally influenced higher need for monitoring and higher perceived control to attend care in Switzerland compared to the USA.

A limitation of our study is its cross-sectional design. Therefore, we are not able to draw conclusions on the temporality of the investigated TPB-related correlates and intention and actual follow-up care attendance. Furthermore, follow-up attendance was self-reported and might not reflect actual attendance correctly. The response rate of 41.1% is relatively low, but in the same range as response rates in questionnaire studies among childhood cancer survivors. 37 Also, AYAs are a heterogeneous and mobile population 34 difficult to reach and include into studies. 38, 39
A strength of our study is the use of the widely used TPB \(^4\) to investigate correlates of intention and actual attendance in AYA cancer survivors. Another strength is the population-based sampling of AYA cancer survivors. Our study participants were comparable to non-participants suggesting that the study sample is representative for AYA cancer survivors in a large and diverse region of Switzerland. Furthermore, we observed similar results in a cohort of Swiss childhood cancer survivors \(^17\), what strengthens our findings.

In conclusion, we found positive attitudes and supportive social norms being associated with higher intention to attend follow-up care, and higher intention being associated with actual follow-up care attendance. Increasing awareness of the importance and benefits of follow-up care among survivors but also family, friends and health care professionals may help to increase follow-up care attendance among AYA cancer survivors.

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**Author Disclosure Statement**

No competing financial interests exist.
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Table 1: Comparison of participants and non-participants of our study in Swiss adolescent and young adult cancer survivors.

|                          | AYA cancer survivors (n = 469) | Participants (n = 160) | Non-participants (n = 309) | p value c |
|--------------------------|--------------------------------|------------------------|---------------------------|-----------|
| **Socio-demographic characteristics** |                                |                        |                           |           |
| Sex                      |                                |                        |                           |           |
| Male                     | 98 (61.3)                      | 210 (68.0)             |                           | 0.110     |
| Female                   | 62 (38.7)                      | 96 (31.0)              |                           |           |
| Age at study             |                                |                        |                           | 0.567     |
| 20-29 years              | 43 (26.9)                      | 74 (24.0)              |                           |           |
| 30-39 years              | 85 (53.1)                      | 180 (58.2)             |                           |           |
| ≥40 years                | 32 (20.0)                      | 55 (17.8)              |                           |           |
| Migration background     | n.a. d                         |                        |                           |           |
| No                       | 125 (78.1)                     |                        |                           |           |
| Yes                      | 35 (21.9)                      |                        |                           |           |
| Educational achievement b,e | n.a. d                 |                        |                           |           |
| Compulsory schooling     | 13 (8.1)                       |                        |                           |           |
| Vocational training      | 74 (46.3)                      |                        |                           |           |
| Upper secondary education| 53 (33.1)                      |                        |                           |           |
| University education     | 19 (11.9)                      |                        |                           |           |
| Employment status b      | n.a. d                         |                        |                           |           |
| Employed                 | 145 (90.6)                     |                        |                           |           |
| Unemployed               | 14 (8.8)                       |                        |                           |           |
| Partnership              | n.a. d                         |                        |                           |           |
| Yes                      | 123 (76.9)                     |                        |                           |           |
| No                       | 37 (23.1)                      |                        |                           |           |
| **Clinical characteristics** |                                |                        |                           | 0.138     |
| Diagnosis (ICCC-3) a     |                                |                        |                           |           |
| Leukemia                 | 13 (8.1)                       | 28 (9.1)               |                           |           |
| Lymphoma                 | 60 (37.5)                      | 91 (29.5)              |                           |           |
| CNS tumour               | 15 (9.4)                       | 36 (11.6)              |                           |           |
| Neuroblastoma            | 2 (1.3)                        | 2 (0.6)                |                           |           |
| Renal tumour             | 3 (1.9)                        | 1 (0.3)                |                           |           |
| Hepatic tumour           | 0 (0.0)                        | 2 (0.6)                |                           |           |
| Bone tumour              | 6 (3.7)                        | 15 (4.9)               |                           |           |
| Soft tissue sarcoma      | 15 (9.4)                       | 17 (5.5)               |                           |           |
| Germ cell tumour         | 46 (28.7)                      | 117 (37.9)             |                           |           |
| Treatment b              |                                |                        |                           | 0.428     |
| Surgery                  | 57 (35.6)                      | 109 (35.3)             |                           |           |
| Chemotherapy             | 36 (22.5)                      | 75 (24.3)              |                           |           |
| Radiotherapy             | 41 (25.6)                      | 60 (19.4)              |                           |           |
# Table 1 continued

|                                | AYA cancer survivors (n = 469) | Participants (n = 160) | Non-participants (n = 309) | p value **c** |
|--------------------------------|--------------------------------|------------------------|-----------------------------|---------------|
|                                | **n (%)**                      | **n (%)**              |                             |               |
| Age at diagnosis                |                                |                        |                             |               |
| 16-21 years                     | 70 (43.8)                      | 122 (39.5)             |                             | 0.373         |
| >21-25 years                    | 90 (56.2)                      | 187 (60.5)             |                             |               |
| Time since diagnosis            |                                |                        |                             | 0.976         |
| 5-10 years                      | 59 (36.9)                      | 111 (36.0)             |                             |               |
| 11-15 years                     | 51 (31.9)                      | 99 (32.0)              |                             |               |
| ≥16 years                       | 50 (31.2)                      | 99 (32.0)              |                             |               |
| Self-reported late effects **b**|                                |                        |                             | n.a. **d**    |
| No                              | 111 (69.4)                     |                        |                             |               |
| Yes                             | 45 (28.1)                      |                        |                             |               |
| Self-reported relapse of cancer |                                |                        |                             | n.a. **d**    |
| No                              | 136 (85.0)                     |                        |                             |               |
| Yes                             | 24 (15.0)                      |                        |                             |               |
| Self-reported second cancer     |                                |                        |                             | n.a. **d**    |
| No                              | 148 (92.5)                     |                        |                             |               |
| Yes                             | 12 (7.5)                       |                        |                             |               |
|                                | **Mean (SD)**                  | **Mean (SD)**          | **p value **c**             |               |
| Age at study                    | 34.0 (5.8)                     | 34.2 (5.6)             | 0.754                       |
| Age at diagnosis                | 21.6 (2.9)                     | 21.7 (2.9)             | 0.706                       |
| Time since diagnosis            | 12.4 (4.8)                     | 12.5 (4.8)             | 0.884                       |

Abbreviations: CNS, central nervous system; ICCC-3, International Classification of Childhood Cancer - Third Edition; n.a., not available; n, number; SD, standard deviation; AYA, adolescent and young adult.

**a** Bone tumours, Neuroblastoma, renal tumours and soft tissue sarcomas were combined in a category called “other tumours” for the analyses.

**b** Missing values; percentages are based on the total number of participants/non-participants.

**c** p value calculated from t test statistics (continuous variables) and chi-square test statistics (categorical variables) comparing participants and non-participants.

**d** Information was not available for non-participants.

**e** Vocational training reference category for the regression analyses.
Table 2: Correlates of intention to attend follow-up care (standardized solution of the structural equation model; n=160).

| Structural model | Standardized coefficient | 95% CI       | p value  | Robust standard error |
|------------------|--------------------------|--------------|----------|-----------------------|
| **Intention**    |                          |              |          |                       |
| Attitude         | 0.32                     | (0.05; 0.60) | 0.020    | 0.14                  |
| Norm             | 0.59                     | (0.41; 0.78) | <0.001   | 0.10                  |
| Control          | -0.13                    | (-0.36; 0.10)| 0.283    | 0.12                  |
| Age at study     | -0.03                    | (-0.28; 0.21)| 0.790    | 0.13                  |
| Sex: female      | -0.02                    | (-0.13; 0.09)| 0.766    | 0.06                  |
| Time since diagnosis | -0.05                   | (-0.29; 0.19)| 0.695    | 0.12                  |
| Late effects     | 0.03                     | (-0.10; 0.17)| 0.647    | 0.07                  |
| Relapse          | 0.16                     | (0.04; 0.28) | 0.007    | 0.06                  |
| New cancer       | 0.02                     | (-0.04; 0.08)| 0.542    | 0.03                  |
| Fear of detecting late effects | 0.00         | (-0.12; 0.12)| 0.969    | 0.06                  |
| **Measurement model** |                        |              |          |                       |
| Attitude         |                          |              |          |                       |
| Indicator A1     | 0.59                     | (0.38; 0.80) | <0.001   | 0.11                  |
| Indicator A2     | 0.61                     | (0.42; 0.79) | <0.001   | 0.10                  |
| Indicator A3     | 0.68                     | (0.54; 0.83) | <0.001   | 0.07                  |
| Indicator A4     | 0.58                     | (0.39; 0.77) | <0.001   | 0.10                  |
| Indicator A5     | 0.50                     | (0.25; 0.75) | <0.001   | 0.13                  |
| Norm             |                          |              |          |                       |
| Indicator N1     | 0.97                     | (0.91; 1.02) | <0.001   | 0.03                  |
| Indicator N2     | 0.80                     | (0.72; 0.88) | <0.001   | 0.04                  |
| Control          |                          |              |          |                       |
| Indicator C1     | 0.63                     | (0.44; 0.82) | <0.001   | 0.10                  |
| Indicator C2     | 0.90                     | (0.70; 1.10) | <0.001   | 0.10                  |
| Intention        |                          |              |          |                       |
| Indicator I1     | 1.00                     | (0.99; 1.00) | <0.001   | 0.00                  |
| Indicator I2     | 0.99                     | (0.97; 1.00) | <0.001   | 0.01                  |
| Covariances      |                          |              |          |                       |
| Attitude         | e.indicator A1, e.indicator A2 | 0.74        | (0.50; 0.98)| <0.001 | 0.12                  |
|                   | e.indicator A3, e.indicator A4 | 0.30        | (0.06; 0.54)| 0.014  | 0.12                  |
Table 2 continued

| Measure | Value | Criterion | Goodness of fit |
|---------|-------|-----------|-----------------|
| $\chi^2$ (85) | 118.3 | $<2df^c$ | good fit |
| RMSEA (90% CI) | 0.05 (0.03; 0.07) | $=0.05$ | good fit |
| SRMR $^a$ | 0.05 | $=0.05$ | good fit |
| CFI | 0.98 | $>0.97$ | good fit |
| TLI | 0.96 | $>0.95$ | acceptable fit |

Abbreviations: CI, confidence interval; $\chi^2$, chi-squared; df, degrees of freedom; RMSEA, root-mean-square error of approximation; SRMR, standardized root-mean-square residual; CFI, Comparative Fit Index; TLI, Tucker Lewis Index.

$^a$ Based on 133 observations, since SRMR can only be obtained without taking into account observations with missing values.

$^b$ Criteria and goodness of fit according to 23.

$^c$ Degrees of freedom = 85 for the structural equation model.

$p$ values $<0.05$ are indicated in bold.
Table 3: Correlates of actual follow-up care attendance (multivariable logistic regression; n=154).

| n = 154                                      | OR    | 95% CI          | p value |
|----------------------------------------------|-------|-----------------|---------|
| Actual follow-up care attendance             |       |                 |         |
| Intention                                    | 14.29 | (5.80; 35.21)   | <0.001  |
| Control                                      | 4.55  | (1.83; 11.31)   | 0.001   |
| Age at study [years]                         | 1.08  | (0.86; 1.37)    | 0.494   |
| Sex: female                                  | 0.80  | (0.19; 3.30)    | 0.755   |
| Time since diagnosis [years]                 | 0.93  | (0.69; 1.26)    | 0.633   |
| Late effects                                 | 10.25 | (1.58; 66.61)   | 0.015   |
| Relapse                                      | 20.69 | (1.27; 337.85)  | 0.033   |
| New cancer                                   | 0.81  | (0.04; 14.99)   | 0.889   |
| Fear of detecting late effects               | 1.47  | (1.00; 2.14)    | 0.049   |

Abbreviations: CI, confidence interval; OR, odds ratio.

p values<0.05 are indicated in bold.
Figure 1: Correlates of intention to attend follow-up care (structural equation model) and actual follow-up care attendance (logistic regression analysis) in Swiss adolescent and young adult cancer survivors according to the theory of planned behaviour.

Ovals indicate latent factors (three correlates and intention), rectangles indicate measured variables (indicators and actual attendance), straight arrows indicate paths included in the structural equation model, curved arrows indicate freed covariances between indicators included in the structural equation model, and dashed lines depict the logistic regression analysis.
Attendance to follow-up care in survivors of adolescent and young adult cancer: application of the theory of planned behaviour

Katharina Roser 1, Julia Baenziger 1, Luzius Mader 1, Salome Christen 1, Silvia Dehler 2,3 and Gisela Michel 1,4,*

1 University of Lucerne, Frohburgstrasse 3, PO Box 4466, 6002 Lucerne, Switzerland
2 Cancer Registry Zurich and Zug, Institute of Surgical Pathology, University Hospital Zurich and Epidemiology, Biostatistics and Prevention Institute, University Zurich, Vogelsangstrasse 10, 8091 Zurich, Switzerland;
3 Departement Gesundheit und Soziales, Abteilung Gesundheit, Bachstrasse 15, 5001 Aarau, Switzerland;
4 Institute of Social and Preventive Medicine, University of Bern, Finkenhubelweg 11, 3012 Bern, Switzerland
* Corresponding author

Corresponding author
Gisela Michel
Department of Health Sciences and Health Policy
University of Lucerne
Frohburgstrasse 3
PO Box 4466
6002 Lucerne
Switzerland.
Phone: +41 41 2295955
Fax: +41 41 2295635
Email: gisela.michel@unilu.ch

Supplementary Material
### Assessment of correlates, intention and actual follow-up care attendance

**Table S1**: Assessment of correlates, intention and actual follow-up care attendance in the questionnaire (English translation, original questionnaire in German; questions developed according to the Theory of Planned Behaviour manual. ¹

| Correlates                                                                 | n   | mean (SD) |
|---------------------------------------------------------------------------|-----|-----------|
| **Attitude**                                                              |     |           |
| *I find regular follow-up...*                                             |     |           |
| 1  Unnecessary (1) - meaningful (7)                                       | 155 | 6.43 (1.28) |
| 2  Bad (1) - good (7)                                                     | 145 | 6.39 (1.15) |
| 3  Unpleasant (1) - Pleasant (7)                                          | 146 | 4.13 (1.92) |
| 4  Boring (1) - interesting (7)                                          | 140 | 4.56 (1.70) |
| *To me, detecting and treating possible late effects of my cancer is...*  |     |           |
| 5  Unimportant (1) - Important (7)                                        | 159 | 6.67 (0.88) |
| **Norm**                                                                  |     |           |
| *Most people that are important to me think I should attend to follow-up care.* |     |           |
| 1  Not true at all (1) - very true (7)                                    | 156 | 4.98 (2.44) |
| *It is expected from me that I attend to follow-up care regularly.*       |     |           |
| 2  Not true at all (1) - very true (7)                                    | 157 | 4.06 (2.45) |
| **Control**                                                               |     |           |
| *For me, attending regular follow up is...*                              |     |           |
| 1  Complicated (1) - easy (7)                                             | 156 | 5.49 (1.69) |
| *It is foremost in my hands whether I regularly attend follow-up or not.* |     |           |
| 2  Stressful (1) - not at all stressful (7)                               | 153 | 4.92 (1.75) |
| 3  Not true at all (1) - very true (7)                                    | 159 | 5.88 (1.7)  |
| **Intention**                                                             |     |           |
| *I intend to attend follow-up next year.*                                 |     |           |
| 1  Not true at all (1) - very true (7)                                    | 157 | 4.66 (2.66) |
| *It is likely that I will attend follow-up within the next year.*         |     |           |
| 2  Not true at all (1) - very true (7)                                    | 158 | 4.76 (2.67) |

| Follow-up care attendance                                                  | n (%) | n (%) |
|---------------------------------------------------------------------------|-------|-------|
| *Do you still attend follow-up care?*                                     |       |       |
| Yes                                                                       | 92 (57.5) | 84 (52.5) |
| Yes, I regularly attend follow-up; intervals between follow-up appointments can be a few months to years. |       |       |
| Yes, I irregularly attend follow-up; I contact my former treating doctor irregularly, especially when I have questions regarding my former illness. | 8 (5.0) |       |
| **No**                                                                    | 68 (42.5) |       |
| No, follow-up is completed; I visit my treating doctor only when I have specific complaints that are associated with my former illness. |       | 27 (16.9) |
| No, follow-up is completed; I never contact my former treating doctor.    |       | 41 (25.6) |

Abbreviations: SD, standard deviation.

Correlates and intention to attend follow-up care were assessed using 7-point Likert scales.
Internal consistency and principal component factor analyses

Table S2: Separate principal component factor analyses for the three correlates (attitude, norm, control) and intention to attend follow-up care.

| Factor            | Eigenvalue | Difference | Proportion | Indicator           | Loading factor 1 | Loading factor 2 | Uniqueness |
|-------------------|------------|------------|------------|---------------------|-----------------|-----------------|------------|
| **Attitude (n = 158)** |            |            |            |                     |                 |                 |            |
| Factor A1         | 2.92       | 1.97       | 0.58       | Indicator A1        | 0.86            | -               | 0.27       |
| Factor A2         | 0.95       | 0.31       | 0.19       | Indicator A2        | 0.88            | -               | 0.23       |
| Factor A3         | 0.64       | 0.30       | 0.13       | Indicator A3        | 0.72            | -               | 0.48       |
| Factor A4         | 0.35       | 0.21       | 0.07       | Indicator A4        | 0.74            | -               | 0.46       |
| Factor A5         | 0.13       | -          | 0.03       | Indicator A5        | 0.59            | -               | 0.65       |
| **Norm (n = 158)** |            |            |            |                     |                 |                 |            |
| Factor N1         | 1.78       | 1.56       | 0.89       | Indicator N1        | 0.94            | -               | 0.11       |
| Factor N2         | 0.22       | -          | 0.11       | Indicator N2        | 0.94            | -               | 0.11       |
| **Control (n = 159)** |            |            |            |                     |                 |                 |            |
| Factor C1         | 1.58       | 0.58       | 0.53       | Indicator C1        | 0.89            | 0.03            | 0.21       |
| Factor C2         | 1.00       | 0.58       | 0.33       | Indicator C2        | 0.89            | -0.01           | 0.21       |
| Factor C3         | 0.42       | -          | 0.14       | Indicator C3        | -0.02           | 1.00            | 0.00       |
| **Control without indicator C3 (n = 159)** |            |            |            |                     |                 |                 |            |
| Factor C1         | 1.60       | 1.20       | 0.80       | Indicator C1        | 0.89            | -               | 0.20       |
| Factor C2         | 0.40       | -          | 0.20       | Indicator C2        | 0.89            | -               | 0.20       |
| **Intention (n = 158)** |            |            |            |                     |                 |                 |            |
| Factor I1         | 1.98       | 1.96       | 0.99       | Indicator I1        | 1.00            | -               | 0.01       |
| Factor I2         | 0.02       | -          | 0.01       | Indicator I2        | 1.00            | -               | 0.01       |
## Confirmatory factor analysis

**Table S3**: Standardized solution of the combined confirmatory factor analysis for the three correlates (attitude, norm, control) and intention to attend follow-up care (maximum likelihood estimation, robust Huber/White/sandwich estimator for estimation of standard errors; n=160).

|                    | Factor loading | 95% CI          | p value | Robust standard error |
|--------------------|----------------|-----------------|---------|-----------------------|
| **Attitude**       |                |                 |         |                       |
| Indicator A1       | 0.64           | (0.46; 0.83)    | <0.001  | 0.09                  |
| Indicator A2       | 0.65           | (0.48; 0.82)    | <0.001  | 0.09                  |
| Indicator A3       | 0.63           | (0.47; 0.79)    | <0.001  | 0.08                  |
| Indicator A4       | 0.55           | (0.37; 0.74)    | <0.001  | 0.09                  |
| Indicator A5       | 0.53           | (0.29; 0.77)    | <0.001  | 0.12                  |
| **Norm**           |                |                 |         |                       |
| Indicator N1       | 0.97           | (0.92; 1.03)    | <0.001  | 0.03                  |
| Indicator N2       | 0.80           | (0.72; 0.88)    | <0.001  | 0.04                  |
| **Control**        |                |                 |         |                       |
| Indicator C1       | 0.80           | (0.53; 1.06)    | <0.001  | 0.13                  |
| Indicator C2       | 0.71           | (0.48; 0.95)    | <0.001  | 0.12                  |
| **Intention**      |                |                 |         |                       |
| Indicator I1       | 0.99           | (0.99; 1.00)    | <0.001  | 0.00                  |
| Indicator I2       | 0.99           | (0.97; 1.00)    | <0.001  | 0.01                  |

|                    | Coefficient    | 95% CI          | p value | Robust standard error |
|--------------------|----------------|-----------------|---------|-----------------------|
| **Covariances**    |                |                 |         |                       |
| e.indicator A1, e.indicator A2 | 0.71 | (0.44; 0.98) | <0.001  | 0.14 |
| e.indicator A3, e.indicator A4 | 0.35 | (0.13; 0.56) | **0.001** | 0.11 |

### Goodness of fit

| Measure                  | Value | Criterion \(^b\) | Goodness of fit \(^b\) |
|--------------------------|-------|------------------|------------------------|
| X² (36)                  | 63.5  | <2df \(^c\)      | good fit               |
| RMSEA (90% CI)           | 0.07  | <0.08            | acceptable fit         |
| SRMR \(^a\)             | 0.04  | <0.05            | good fit               |
| CFI                      | 0.98  | >0.97            | good fit               |
| TLI                      | 0.97  | >0.95            | acceptable fit         |

Abbreviations: CI, confidence interval; \(X^2\), chi-squared; df, degrees of freedom; RMSEA, root-mean-square error of approximation; SRMR, standardized root-mean-square residual; CFI, Comparative Fit Index; TLI, Tucker Lewis Index.

\(^a\) Based on 133 observations, since SRMR can only be obtained without taking into account observations with missing values.

\(^b\) Criteria and goodness of fit according to 2.

\(^c\) Degrees of freedom = 36 for the combined confirmatory factor analysis.
Table S4 Unstandardized solution of the combined confirmatory factor analysis for the three correlates (attitude, norm, control) and intention to attend follow-up care (maximum likelihood estimation, robust Huber/White/sandwich estimator for estimation of standard errors; n=160).

| Attitude          | Factor loading | 95% CI     | p value | Robust standard error |
|-------------------|----------------|------------|---------|-----------------------|
| Indicator A1      | 1.00           | (constrained) |         |                       |
| Indicator A2      | 0.93           | (0.73; 1.13) | <0.001  | 0.10                  |
| Indicator A3      | 1.46           | (0.66; 2.26) | <0.001  | 0.41                  |
| Indicator A4      | 1.14           | (0.53; 1.76) | <0.001  | 0.31                  |
| Indicator A5      | 0.56           | (0.27; 0.85) | <0.001  | 0.15                  |
| Norm              | 1.00           | (constrained) |         |                       |
| Indicator N1      | 0.82           | (0.70; 0.95) | <0.001  | 0.06                  |
| Indicator N2      | 0.93           | (0.31; 1.54) | 0.003   | 0.31                  |
| Control           | 1.00           | (constrained) |         |                       |
| Indicator C1      | 0.93           | (0.53; 1.76) | <0.001  | 0.31                  |
| Indicator C2      | 0.99           | (0.97; 1.02) | <0.001  | 0.01                  |

| Covariances       | Coefficient   | 95% CI     | p value | Robust standard error |
|-------------------|---------------|------------|---------|-----------------------|
| Attitude          | e.indicator A1, e.indicator A2 | 0.63 | (0.23; 1.03) | 0.002 | 0.20 |
|                   | e.indicator A3, e.indicator A4 | 0.72 | (0.13; 1.32) | 0.017 | 0.30 |

Goodness of fit

| Measure          | Value | Criterion b | Goodness of fit b |
|------------------|-------|-------------|-------------------|
| X² (36)          | 63.5  | <2df c      | good fit          |
| RMSEA (90% CI)   | 0.07  | <0.08       | acceptable fit    |
| SRMR a           | 0.04  | <0.05       | good fit          |
| CFI              | 0.98  | >0.95       | good fit          |
| TLI              | 0.97  | >0.95       | acceptable fit    |

Abbreviations: CI, confidence interval; X², chi-squared; df, degrees of freedom; RMSEA, root-mean-square error of approximation; SRMR, standardized root-mean-square residual; CFI, Comparative Fit Index; TLI, Tucker Lewis Index.

a Based on 133 observations, since SRMR can only be obtained without taking into account observations with missing values.
b Criteria and goodness of fit according to ².
c Degrees of freedom = 36 for the combined confirmatory factor analysis.
Table S5: Correlates of intention to attend follow-up care (univariable linear regression analyses) and actual follow-up care attendance (univariable logistic regression analyses).

|                                      | Univariable linear regression analyses for intention to attend follow-up care | Univariable logistic regression analyses for actual follow-up care attendance |
|--------------------------------------|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------|
|                                      | Coefficient | 95% CI            | p value \(^a\) | Coefficient | 95% CI            | p value \(^a\) |
| Age at study [years]                 | -0.07        | (-0.09; -0.04)    | <0.001          | 0.90         | (0.85; 0.95)      | <0.001          |
| Sex: female                          | 0.10         | (-0.22; 0.42)     | 0.534           | 1.04         | (0.55; 1.98)      | 0.909           |
| Migration background                 | 0.22         | (-0.16; 0.60)     | 0.253           | 1.56         | (0.71; 3.40)      | 0.268           |
| Educational achievement              |             | 0.879             |                 |             |                  |                 |
|                                      | Vocational training | reference |                  | University education | reference |                 |
| Compulsory schooling                 | -0.17        | (-0.79; 0.45)     | 0.34            | (0.10; 1.20) |
| Upper secondary education            | 0.05         | (-0.31; 0.41)     | 1.36            | (0.66; 2.82) |
| University education                 | -0.12        | (-0.63; 0.40)     | 1.31            | (0.46; 3.69) |
| Employment status: employed          | -0.41        | (-0.96; 0.14)     | 0.140           | 0.51         | (0.15; 1.69)      | 0.268           |
| Partnership: yes                     | 0.05         | (-0.32; 0.42)     | 0.780           | 1.38         | (0.66; 2.89)      | 0.389           |
| Diagnosis                            |             | 0.224             |                 |             |                  | 0.110           |
|                                      | CNS tumour | reference |                  | Germ cell tumour | reference |                 |
|                                      |             |                    |                 | Leukemia | reference |                 |
|                                      | -0.34       | (-0.94; 0.26)     | 0.31            | (0.08; 1.10) |
|                                      | -0.02       | (-0.79; 0.76)     | 0.58            | (0.12; 2.88) |
|                                      | 0.09        | (-0.49; 0.67)     | 0.73            | (0.21; 2.57) |
|                                      | -0.25       | (-0.91; 0.40)     | 0.31            | (0.08; 1.24) |
|                                      |             |                    |                 |             | 0.440             | 0.857           |
| Treatment                            |             |                    |                 |             |                  |                 |
|                                      | Surgery    | reference |                  | Chemotherapy | reference |                 |
|                                      | -0.14       | (-0.56; 0.28)     | 1.15            | (0.51; 2.58) |
|                                      | -0.05       | (-0.10; 0.01)     | 0.102           | 0.96        | (0.86; 1.07)      | 0.425           |
|                                      | -0.08       | (-0.11; -0.05)    | <0.001          | 0.87        | (0.81; 0.93)      | <0.001          |
|                                      | 0.32        | (-0.03; 0.66)     | 0.073           | 2.61        | (1.22; 5.56)      | 0.013           |
|                                      | 0.78        | (0.34; 1.22)      | 0.001           | 22.33       | (2.93; 170.07)    | 0.003           |
|                                      | 0.71        | (0.10; 1.32)      | 0.023           | 4.02        | (0.85; 19.01)     | 0.079           |
|                                      | 0.10        | (0.03; 0.18)      | 0.007           | 1.26        | (1.07; 1.47)      | 0.005           |

Abbreviations: CI, confidence interval; OR, odds ratio. p values<0.05 are indicated in bold.

\(^a\) Overall p values are calculated using Wald tests.
Theory of Planned Behaviour

Figure S1: Theory of Planned Behaviour applied to follow-up care attendance in Swiss adolescent and young adult cancer survivors.

- **Attitude**: Person’s favourable or unfavourable opinions about follow-up care attendance
- **Norm**: Perceived expectations among the social environment to attend follow-up care
- **Intention**: Intention to attend follow-up care
- **Control**: Perceived easiness or difficulty to attend follow-up care
- **Attendance**: Actual follow-up care attendance
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