Supplement 1. Secondary outcomes

Feeling informed

How well informed the subject felt about their (child's) heart defect (1 question), the risks thereof (1 question) and treatment options (1 question) was assessed using 5-point Likert scales (Supplement 2).

Experiences with patient information

Subjects were asked to indicate whether they had experienced contradictions in the information they received from various sources using a 5-point Likert scale (Supplement 2).

Preference for involvement

Preferences for involvement in own care and decision-making were assessed using the Autonomy Preference Index[30] and the Control Preferences Scale.[31,32] A higher score on the Autonomy Preference Index indicates a stronger preference for more involvement/autonomy.

Anxiety and depression

Anxiety and depression were assessed using the Hospital Anxiety and Depression Scale (HADS).[31,32]

Health-related mental quality of life

Health-related mental quality of life was assessed using the Mental Component of the Dutch version of the Short Form 36 Health Survey (SF-36).[33,34] Total Mental

1

Component raw scores as well as raw scores for each of its subscales were summed and transformed to a 0-100 scale.

Satisfaction with the information portal (only intervention group)

Subjects were asked to rate the contents (1 question) and design (1 question) of the information portal on a 1-10 scale (Supplement 2).

30   Ende J, Kazis L, Ash A, et al. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *J Gen Intern Med* 1989;**4**:23-30.

31   Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. *Can J Nurs Res* 1997;**29**:21-43.

32   Pieterse AH, Baas-Thijssen MC, Marijnen CA, et al. Clinician and cancer patient views on patient participation in treatment decision-making: a quantitative and qualitative exploration. *Br J Cancer* 2008;**99**:875-82.

33   Ware JE, Jr., Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992;**30**:473-83.

34   Aaronson NK, Muller M, Cohen PD, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. *J Clin Epidemiol* 1998;**51**:1055-68.

Supplement 2. Questionnaires used in this study that have not been previously published (translated to English)

<u>Disease-specific knowledge (primary outcome)</u>

1 **The heart has two outflow valves, the aortic valve and the pulmonary valve. Which valve is affected in your case?**
   ☐ The aortic valve   (correct answer depends
   ☐ The pulmonary valve   on the patients personal
   ☐ Both   condition, as recorded by
   ☐ I don't know   the (pediatric) cardiologist)

2 **My heart valve defect concerns a:**
   ☐ Narrowing (stenosis)   (correct answer depends
   ☐ Leakage (regurgitation)   on the patients personal
   ☐ Both   condition, as recorded by
   ☐ I don't know   the (pediatric) cardiologist)

3 **People who have been diagnosed with a heart valve defect: (only one answer possible)**
   ☐ Usually do not need to undergo surgery.   (incorrect)
   ☐ Usually need to undergo 1 or multiple surgeries during   (correct)
      their lifetime

4 **People with a heart valve defect usually do well in <u>daily functioning.</u>**
   ☐ True   (correct)
   ☐ False   (incorrect)
   ☐ I don't know   (incorrect)

5 **People with a heart valve defect <u>never</u> need to take this into account when considering <u>work/carreer</u>.**
   ☐ True   (incorrect)
   ☐ False   (correct)
   ☐ I don't know   (incorrect)

6 **What is the <u>most important</u> purpose of your check-ups?**
   ☐ A routine check-up, without a specific purpose.   (incorrect)
   ☐ Personal reassurance.   (incorrect)
   ☐ To detect a deterioration in your condition.   (correct)
   ☐ To continue treatment with the latest techniques. (incorrect)

3

Supplemental material

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Open Heart

7 **Which of the following symptoms may indicate deterioration of your condition, in which case you should contact the cardiologist?**

1. Shortness of breath
2. Getting exhausted sooner upon exertion
3. Fainting

☐ 1 and 2   (incorrect)
☐ 2 and 3   (incorrect)
☐ 1 and 3   (incorrect)
☐ All (1, 2 and 3)   (correct)
☐ I don't know   (incorrect)

Feeling informed (secondary outcome)

1. **Do you feel like you have sufficient knowledge about your heart valve defect?**

Strongly disagree   1   2   3   4   5   Strongly agree

2. **Do you feel like you have sufficient knowledge about the risks of your heart valve defect?**

Strongly disagree   1   2   3   4   5   Strongly agree

3. **Do you feel like you have sufficient knowledge about the (possible) treatment options for your heart valve defect?**

Strongly disagree   1   2   3   4   5   Strongly agree

Experiences with patient information (secondary outcome)

1. **The information about my condition and the treatment options that I obtained from different care providers and/or other sources of information did not always correspond.**

Strongly disagree   1   2   3   4   5   Strongly agree

Satisfaction with the information portal (secondary outcome, only intervention group)

1. **How would you rate the website on a scale from 1 to 10 with regard to:**

Contents: 1   2   3   4   5   6   7   8   9   10

Design: 1   2   3   4   5   6   7   8   9   10

Supplement 3. Baseline characteristics of the subjects in the intervention group who visited the information portal and those who did not. PV=pulmonary valve. ToF=tetralogy of Fallot. AV=aortic valve.

	Intervention group:		p-value
	Did not visit portal n=59	Visited portal n=63	
Age group			0.679
-Children	40.7% (24)	46% (29)	
-Adults	59.3% (35)	54% (34)	
Male sex	49.2% (29)	31.7% (20)	0.146
Diagnosis			0.196
-PV disease	57.6% (34)	73% (46)	
-ToF	28.8% (17)	47.6% (30)	
-AV disease	39% (23)	25.4% (16)	
-PV+AV disease	3.4% (2)	1.6% (1)	
Educational level			0.083
-Elementary	3.6% (2)	0% (0)	
-Lower vocational	10.9% (6)	4.8% (3)	
-Lower secondary	9.1% (5)	3.2% (2)	
-Intermediate vocational	32.7% (18)	33.9% (21)	
-Higher secondary	14.5% (8)	6.5% (4)	
-Higher vocational	18.2% (10)	37.1% (23)	
-University	10.9% (6)	14.5% (9)	