

Additional file 2. Template of the survey to patients

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
The questions were, generally, easy to understand.					
The questions were, generally, easy to answer.					
If my doctor asks me these questions, it may help to improve the quality of my care.					
The questions asked in the questionnaire are usually dealt with during the clinical consultation.					
<p>Bearing in mind that the purpose of the questionnaire is to identify unmet needs:</p> <p>Do you think are there other questions we should include in the questionnaire?</p>					

Additional file 3. Template of the survey to health care personnel

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
In general, the questions were easy to understand for the patient.					
The questions asked in the questionnaire are usually dealt with during the clinical consultation.					

**Additional file 4.** Template of the interview to assess face validity, applicability, relevance and acceptability of the tool among health care personnel

Face validity: Needs Assessment Tool: Progressive disease – Heart failure (NAT: PD-HF)

Interview code \_\_\_\_\_

Date \_\_\_\_\_ Time \_\_\_\_\_

**General characteristics of the staff**

Professional category	sex
<input type="checkbox"/> physician cardiology	<input type="checkbox"/> female
<input type="checkbox"/> physician palliative care	<input type="checkbox"/> male
<input type="checkbox"/> nurse cardiology	
<input type="checkbox"/> nurse palliative care	professional experience
<input type="checkbox"/> psychologist	
<input type="checkbox"/> social worker	<input type="checkbox"/> < 5
<input type="checkbox"/> general practitioner	<input type="checkbox"/> 5-10
<input type="checkbox"/> others (e.g. medical student)	<input type="checkbox"/> > 10

**Interview**

<b>Face validity</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>
1) The tool measures unmet needs of patients with heart failure and their caregivers → comment:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Applicability</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>
1) The tool is easy to use → comment:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) Different professional groups can fill out the tool → comment: 2.a Which professional group should fill out the tool?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) The tool instructions are easy to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) The tool instructions are helpful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) A special training is necessary to fill out the tool	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) There are some difficulties in using the tool → If yes, which:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Relevance</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>

1) Some questions are irrelevant and can be left out → If yes, which ones	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Acceptability</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>
1) Filling out the tool does not take too much time and can be integrated into daily routine clinical practice  1.a) When should the tool be applied?  1.b) How often should the tool be applied?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) I feel uncomfortable asking some of the questions → If yes, which and why:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Additional file 5.** Original version (English) of the “Needs Assessment Tool: Progressive Disease-Heart Failure (NAT: PD-HF)”.

## NEEDS ASSESSMENT TOOL: PROGRESSIVE DISEASE – HEART FAILURE (NAT: PD-HF) USER GUIDE

### Purpose of the NAT: PD-HF

- Used in both generalist and specialist settings, the Needs Assessment Tool: Progressive Disease – Heart Failure (NAT: PD-HF) can assist in matching the types and levels of need experienced by people with heart failure and their caregivers with the most appropriate people or services to address those needs.
- In generalist settings (eg general practice and cardiology), the NAT: PD-HF can be used to determine which needs may be met in that setting and which needs are more complex and may be better managed by specialists.
- In specialist settings (eg specialist palliative care services), the NAT: PD-HF can assist in determining when complex needs have been met and act as a discharge planning tool, or to identify the need for ongoing support.
- The NAT: PD-C is an important tool for facilitating communication between primary and specialist care providers about patient needs and actions taken to address these.

### Completing the NAT: PD-HF

The NAT: PD-HF is a one-page assessment tool that can be completed by health professionals across a range of disciplines. When completing the NAT: PD-HF, the following steps should be followed:

1. ASSESS patient/caregiver level of concern FOR EVERY ITEM, using the response options: “none”, “some/potential for” or “significant”.
2. CONSIDER the range of issues within each domain that apply to a person at this stage of their illness. Prompts are provided on a separate page to help you.
3. ACT on each need where you identified some concern (“some/potential for” or “significant”). Your actions may include: directly managed by you, managed by another member of your care team, or referral to someone outside your care team. Record your action on the NAT: PD-HF.
4. REFER if required by completing the referral section at the bottom of the tool, ensuring that information regarding the type of referral, the priority of the referral and client knowledge of the referral is included.
5. INFORM other members of the care team of the outcomes of the needs assessment by:
  - a. Filing one copy of the NAT: PD-HF in the patient’s medical file.
  - b. Sending a copy to the person’s GP/cardiologist/other specialist.
  - c. If a referral is required, forwarding a copy to the referee.
6. REASSESS needs by completing the NAT: PD-HF approximately monthly or when the patient’s or family’s situation, or functional status changes.

# NEEDS ASSESSMENT TOOL : PROGRESSIVE DISEASE HEART FAILURE (NAT: PD-HF)

COMPLETE ALL SECTIONS

PATIENT NAME: \_\_\_\_\_

DATE: \_\_\_\_\_ DIAGNOSIS: \_\_\_\_\_

PATIENT/ADDRESS LABEL
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**SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT**

	Yes	No	If yellow boxes are ticked, consider assessment by SPCS
1. Does the patient have a caregiver readily available if required?	<input type="checkbox"/>	<input type="checkbox"/>	
2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)?	<input type="checkbox"/>	<input type="checkbox"/>	
3. Do you require assistance in managing the care of this patient and/or family?	<input type="checkbox"/>	<input type="checkbox"/>	

**SECTION 2: PATIENT WELLBEING (Refer to the back page for assistance)**

	Level of Concern			Action Taken		
	None	Some/ Potential	Significant	Directly managed	Managed by other care team member	Referral required
1. Is the patient experiencing unresolved physical symptoms (including problems with breathlessness, pain, fatigue, nausea, oedema, insomnia or cough)?						
2. Does the patient have problems with daily living activities?						
3. Does the patient have psychological symptoms that are interfering with wellbeing or relationships?						
4. Does the patient have concerns about how to manage his/her medication and treatment regimes?						
5. Does the patient have concerns about spiritual or existential issues?						
6. Does the patient have financial or legal concerns that are causing distress or require assistance?						
7. From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?						
8. Does the patient require information about: <input type="checkbox"/> The prognosis <input type="checkbox"/> Treatment options <input type="checkbox"/> Advance directive/resuscitation preferences <input type="checkbox"/> Financial/legal issues (tick any options that are relevant) <input type="checkbox"/> Heart disease <input type="checkbox"/> Medical/health/support services <input type="checkbox"/> Social/emotional issues						

COMMENTS: \_\_\_\_\_

**SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT (Refer to the back page for assistance)**

	Level of Concern			Action Taken		
	None	Some/ Potential	Significant	Directly managed	Managed by other care team member	Referral required
Who provided this information? (please tick one) <input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Both						
1. Is the caregiver or family distressed about the patient's physical symptoms?						
2. Is the caregiver or family having difficulty providing physical care?						
3. Is the caregiver or family having difficulty coping?						
4. Is the caregiver have difficulty managing the patient's medication and treatment regimes?						
5. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?						
6. Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems?						
7. Does the caregiver require information: <input type="checkbox"/> The prognosis <input type="checkbox"/> Advance directive/resuscitation preferences <input type="checkbox"/> Medical/health/support services <input type="checkbox"/> Heart disease (tick any options that are relevant) <input type="checkbox"/> Treatment options <input type="checkbox"/> What to do in event of patient's death <input type="checkbox"/> Social/emotional issues <input type="checkbox"/> Financial /legal issues						

COMMENTS: \_\_\_\_\_

**SECTION 4: CAREGIVER WELLBEING (Refer to the back page for assistance)**

	Level of Concern			Action Taken		
	None	Some/ Potential	Significant	Directly managed	Managed by other care team member	Referral required
Who provided this information? (please tick one) <input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Both						
1. Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning?						
2. Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?						

COMMENTS: \_\_\_\_\_

**IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE, PLEASE COMPLETE THIS SECTION**

1. Referral to: (Name) _____	
2. Referral to: (Specialty) <input type="checkbox"/> General practitioner <input type="checkbox"/> Social worker <input type="checkbox"/> Psychologist <input type="checkbox"/> Specialist palliative care service <input type="checkbox"/> Cardiologist <input type="checkbox"/> Other _____	
3. Priority of assessment needed: <input type="checkbox"/> Urgent (within 24 hours) <input type="checkbox"/> Semi-Urgent (2-7 days) <input type="checkbox"/> Non-Urgent (next available)	
4. Discussed the referral with the client. <input type="checkbox"/> Yes <input type="checkbox"/> No	
5. Client consented to the referral. <input type="checkbox"/> Yes <input type="checkbox"/> No	
6. Referral from: Name: _____ Position: _____ Signature: _____	

## ISSUES TO CONSIDER WHEN RATING THE LEVEL OF CONCERN

### PATIENT WELLBEING

#### Physical symptoms

- Does the patient present with unresolved physical symptoms such as drowsiness, fatigue, dyspnoea, vomiting/nausea, persistent cough, pain, oedema, constipation, sleep problems or loss appetite?

#### Activities of daily living

- Is the patient having difficulty with toileting, showering, bathing, or food preparation?
- Is there a caregiver to assist the patient?

#### Psychological

- Is the patient experiencing sustained lowering of mood, tearfulness, guilt or irritability, loss of pleasure or interest in usual activities?
- Is the patient experiencing feelings of apprehension, tension, anger, fearfulness or nervousness, hopelessness or a sense of isolation?
- Is the patient requesting a hastened death?

#### Medication and treatment

- Is the patient able to manage complex medication and treatment regimes?

#### Spiritual/Existential

- Is the patient feeling isolated or hopeless?
- Does the patient feel that life has no meaning or that his/her life has been wasted?
- Does the patient require assistance in finding appropriate spiritual resources or services?

#### Financial/Legal

- Are there financial concerns relating to loss of income or costs of treatment, travel expenses, or equipment?
- Is the family socio-economically disadvantaged?
- Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans?
- Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these?

#### Health Beliefs, Social and Cultural

- Does the patient or family have beliefs or attitudes that make health care provision difficult?
- Are there any language difficulties? Does the patient or family require a translator?
- Is the family preventing information about prognosis from being disclosed to the patient?
- Does the information have to be passed on to a particular member of the family or cultural group?
- Is the patient or family feeling socially isolated?
- Does the family live more than 50km from the primary service provider?
- Is the patient of Aboriginal or Torres Strait Islander descent?
- Is the patient over 75 years of age? (NB: older patients are under-represented in SPCs.)

#### Information

- Does the patient want more information about the course and prognosis of the disease and treatment options?
- Is the patient aware of the various care services available to assist them and do they need assistance in accessing these? (eg financial and legal assistance, psychological services, support groups, pastoral care.)

### ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT

#### Physical symptoms

- Are the patient's physical symptoms causing the caregiver and family distress?

#### Providing physical care

- Is the caregiver having difficulty coping with activities of daily living or practical issues such as equipment and transport?

#### Psychological

- Is the caregiver having difficulty coping with the patient's psychological symptoms?
- Is the caregiver requesting a hastened death for the patient?

#### Medication and treatment

- Is the caregiver having difficulty managing complex medication and treatment regimes?

#### Family and Relationships

- Is there any communication breakdown or conflict between patient and family over prognosis, treatment options or care giving roles?
- Is the patient particularly concerned about the impact of the illness on the caregiver or family?

#### Information

- Does the caregiver or family want more information about the course and prognosis of the disease and treatment?
- Is the caregiver or family aware of the care services available to assist them and do they need assistance in accessing these? (eg respite, financial and legal services, psychological services, support groups, pastoral care.)

### CAREGIVER WELLBEING

#### Physical and psychosocial

- Is the caregiver experiencing physical symptoms eg fatigue, physical strain, blood pressure/heart problems, stress related illness, or sleep disturbances?
- Is the caregiver feeling depressed, hopeless, fearful, nervous, tense, angry, irritable or critical of others, or overwhelmed?
- Does the caregiver have spiritual/existential issues that are of concern?

#### Bereavement Grief (pre and post death)

- Is the caregiver or family experiencing intrusive images, severe pangs of emotion, denial of implications of loss to self and neglect of necessary adaptive activities at home or work?

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Further copies are available at: <http://www.newcastle.edu.au/research-centre/cherp/professional-resources>

## Additional file 6. Changes made for the cultural adaptation

### ISSUES TO CONSIDER WHEN RATING THE LEVEL OF CONCERN

PATIENT WELLBEING	
Physical symptoms	<ul style="list-style-type: none"> <li>Does the patient present with unresolved physical symptoms such as drowsiness, fatigue, dyspnoea, vomiting/nausea, persistent cough, pain, oedema, constipation, sleep problems or loss appetite?</li> </ul>
Activities of daily living	<ul style="list-style-type: none"> <li>Is the patient having difficulty with toileting, showering, bathing, or food preparation?</li> <li>Is there a caregiver to assist the patient?</li> </ul>
Psychological	<ul style="list-style-type: none"> <li>Is the patient experiencing sustained lowering of mood, tearfulness, guilt or irritability, loss of pleasure or interest in usual activities?</li> <li>Is the patient experiencing feelings of apprehension, tension, anger, fearfulness or nervousness, hopelessness or a sense of isolation?</li> <li>Is the patient requesting a hastened death?</li> </ul>
Medication and treatment	<ul style="list-style-type: none"> <li>Is the patient able to manage complex medication and treatment regimes?</li> </ul>
Spiritual/Existential	<ul style="list-style-type: none"> <li>Is the patient feeling isolated or hopeless?</li> <li>Does the patient feel that life has no meaning or that his/her life has been wasted?</li> <li>Does the patient require assistance in finding appropriate spiritual resources or services?</li> </ul>
Financial/Legal	<ul style="list-style-type: none"> <li>Are there financial concerns relating to loss of income or costs of treatment, travel expenses, or equipment?</li> <li>Is the family socio-economically disadvantaged?</li> <li>Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans?</li> <li>Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these?</li> </ul>
Health Beliefs, Social and Cultural	<ul style="list-style-type: none"> <li>Does the patient or family have beliefs or attitudes that make health care provision difficult?</li> <li>Are there any language difficulties? Does the patient or family require a translator?</li> <li>Is the family preventing information about prognosis from being disclosed to the patient?</li> <li>Does the information have to be passed on to a particular member of the family or cultural group?</li> <li>Is the patient or family feeling socially isolated?</li> <li>Does the family live more than 50km from the primary service provider?</li> <li>Is the patient of Aboriginal or Torres Strait Islander descent?</li> <li>Is the patient over 75 years of age? (NB: older patients are under-represented in SPCs.)</li> </ul>
Information	<ul style="list-style-type: none"> <li>Does the patient want more information about the course and prognosis of the disease and treatment options?</li> <li>Is the patient aware of the various care services available to assist them and do they need assistance in accessing these? (eg financial and legal assistance, psychological services, support groups, pastoral care.)</li> </ul>

We changed 'translator' (written translation) to 'interpreter' (oral, real time translation)

Living more than 50 km from the primary service provider is a very rare scenario in Switzerland. Therefore, we replaced it by: Does the patient have difficulty reaching and accessing primary care? (e.g., organization of transportation, no primary care physician, no trust in primary care physician).

Aborigine or Torres Strait Island descent is not applicable to the population of German-speaking Europeans. Therefore, we sought for groups that are relevant in Switzerland, e.g. immigrant or immigrant descents.



**Additional file 7. Table 1.** Matrix of the weights used to assess inter-rater reliability and test-retest reliability

	No concern	Some/potential concern	Significant concern
No concern	1	0.2	0
Some/potential concern	0.2	1	0.8
Significant concern	0	0.8	1

Additional file 8. Table 2. Frequency of answers from the first application of the tool

	None	Some/potential	Significant
<b>Section 2. Patient wellbeing (n=70)</b>			
1. Is the patient experiencing unresolved physical symptoms (including problems with breathlessness, pain, fatigue, nausea, edema, insomnia, or cough)?	28 (40%)	38 (54%)	4 (6%)
2. Does the patient have problems with daily living activities?	60 (86%)	9 (13%)	1 (1%)
3. Does the patient have psychological symptoms that are interfering with well-being or relationships?	40 (57%)	30 (43%)	0 (0%)
4. Does the patient have concerns about how to manage his/her medication and treatment regimens?	67 (96%)	3 (4%)	0 (0%)
5. Does the patient have concerns about spiritual or existential issues?	64 (91%)	6 (9%)	0 (0%)
6. Does the patient have financial or legal concerns that are causing distress or require assistance?	51 (73%)	19 (27%)	0 (0%)
7. From the health delivery point of view, are there health beliefs, cultural, or social factors involving the patient or family that are making care more complex?	64 (91%)	6 (9%)	0 (0%)
<b>Section 3. Ability of caregiver or family to care for patient (n=67)</b>			
1. Is the caregiver or family distressed about the patient's physical symptoms?	66 (99%)	1 (1%)	0 (0%)
2. Is the caregiver or family having difficulty providing physical care?	43 (64%)	24 (36%)	0 (0%)
3. Is the caregiver or family having difficulty coping?	49 (73%)	18 (27%)	0 (0%)
4. Is the caregiver having difficulty managing the patient's medication and treatment regimens?	67 (100%)	0 (0%)	0 (0%)
5. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?	58 (87%)	9 (13%)	0 (0%)
6. Is the family currently experiencing problems that are interfering with their functioning or interpersonal relationships or is there a history of such problems? (n=70)	55 (79%)	15 (21%)	0 (0%)
<b>Section 4. Caregiver wellbeing (n=67)</b>			
1. Is the caregiver or family experiencing physical, practical, spiritual, existential, or psychological problems that are interfering with their well-being or functioning?	59 (88%)	8 (12%)	0 (0%)

	Yes	No
<b>Does the patient require information about: (n=70)</b>		
Heart disease	3 (4%)	67 (96%)
Treatment options	4 (6%)	66 (94%)
Financial/legal issues	16 (23%)	54 (77%)
Living will, life-extending measures	6 (9%)	64 (91%)
Prognosis	3 (4%)	67 (96%)
Medical/health/support services	5 (7%)	65 (93%)
Social/emotional issues	2 (3%)	68 (97%)

**Additional file 9. Table 3.** Sensitivity analysis to assess the inter-rater reliability for each one of second evaluators.

	Cohen's kappa for second evaluator #1	Cohen's kappa for second evaluator #2	higher kappa obtained by:
<b>Section 2. Patient wellbeing</b>			
1. Is the patient experiencing unresolved physical symptoms (including problems with breathlessness, pain, fatigue, nausea, edema, insomnia, or cough)?	0.38	0.46	evaluator #2
2. Does the patient have problems with daily living activities?	0.58	0.58	equal
3. Does the patient have psychological symptoms that are interfering with well-being or relationships?	0.66	0.68	
4. Does the patient have concerns about how to manage his/her medication and treatment regimens?	1.00	0.48	evaluator #1
5. Does the patient have concerns about spiritual or existential issues?	0.88	0.88	equal
6. Does the patient have financial or legal concerns that are causing distress or require assistance?	0.83	0.85	evaluator #2
7. From the health delivery point of view, are there health beliefs, cultural, or social factors involving the patient or family that are making care more complex?	0.00	0.20	evaluator #2
<b>Section 3. Ability of caregiver or family to care for patient</b>			
1. Is the caregiver or family distressed about the patient's physical symptoms?	1.00	0.70	evaluator #1
2. Is the caregiver or family having difficulty providing physical care?	0.77	0.77	equal
3. Is the caregiver or family having difficulty coping?	1.00	0.72	evaluator #1
4. Is the caregiver having difficulty managing the patient's medication and treatment regimens?	1.00	1.00	equal
5. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?	1.00	0.51	evaluator #1
6. Is the family currently experiencing problems that are interfering with their functioning or interpersonal relationships or is there a history of such problems?	0.86	0.44	evaluator #1
<b>Section 4. Caregiver wellbeing</b>			
1. Is the caregiver or family experiencing physical, practical, spiritual, existential, or psychological problems that are interfering with their well-being or functioning?	0.71	0.80	evaluator #2