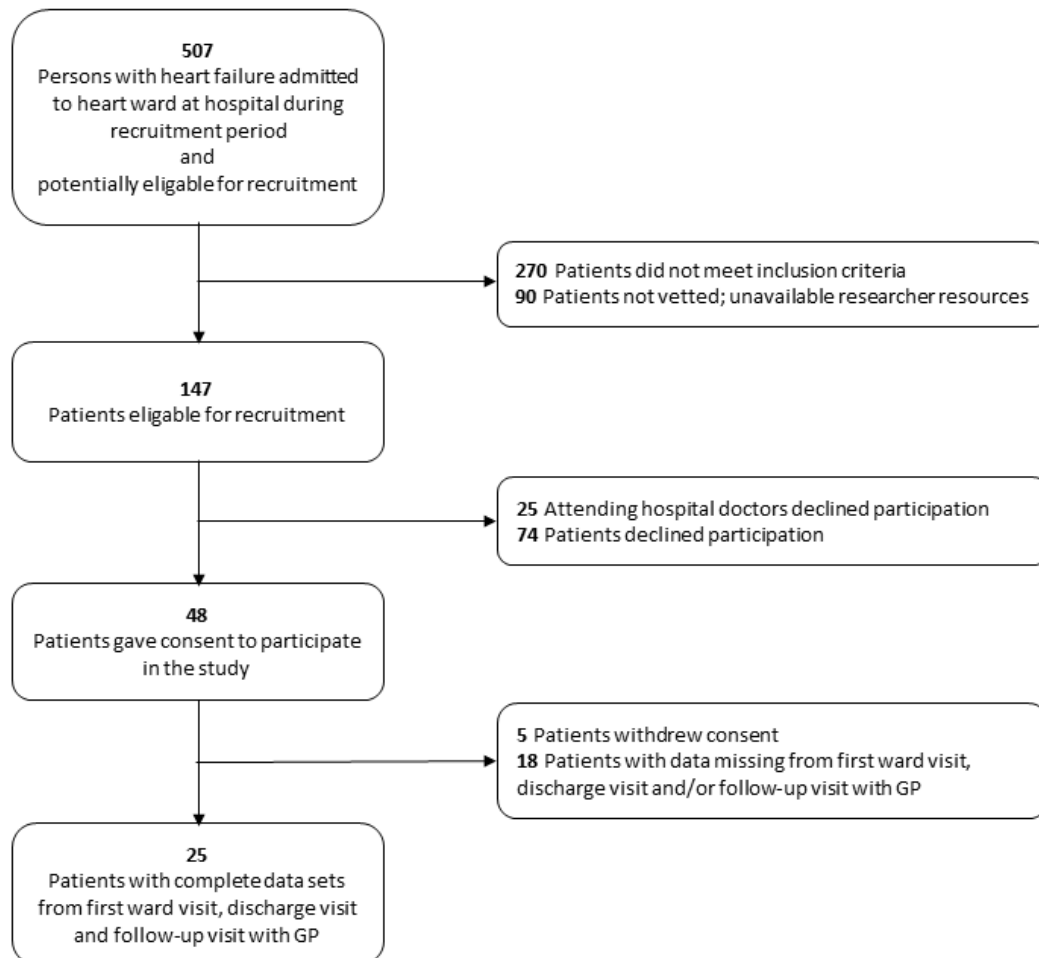


SUPPLEMENTARY MATERIAL

What do patients with heart failure disclose about medication adherence at home to their hospital and primary care doctors?

S1. Flowchart of recruitment and selection of data

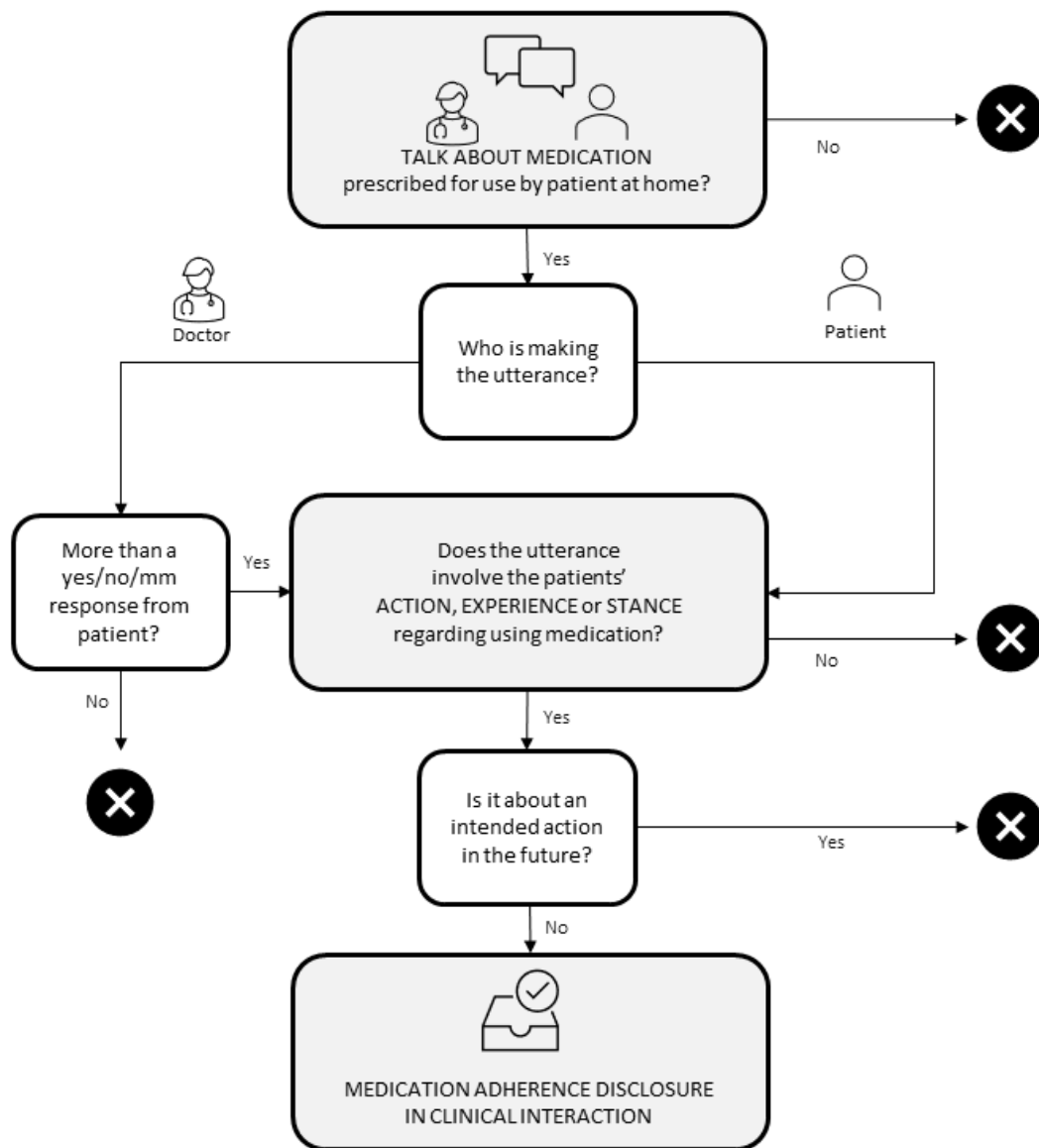


S2. Detailed patient demographics

PATIENTS: Persons (65 years or older) diagnosed with heart failure	n=25
Female, n (%)	8 (32%)
Age, median (min-max)	76 (67-90)
Cognitive function ¹ , median score (min-max)	23 (16-30)
Living alone, n (%)	10 (40%)
Norwegian as mother tongue	24 (96%)
Education, primary school level	6 (24%)
Education, secondary school level	12 (48%)
Education, university level (Bachelor or Master level)	7 (28%)
Work experience from health care	2 (8%)
Diagnosed with HF more than 3 months ago, n (%)	15 (60%)
Ejection fraction (EF%) ² below 35%	11 (44%)
Number of medications at hospital admission ^{2,3} , median (min-max)	6 (0-14)
Number of medications ^{2,3} at hospital discharge, median (min-max)	8 (4-16)
Diagnoses according to discharge letter, median (min-max)	3 (1-6)
Days from hospital admission to hospital discharge, median (min-max)	6 (1-20)
Days between hospital discharge and follow-up visit with GP, median (min-max)	10 (2-43)
HOSPITAL DOCTORS	n=23
Female, n (%)	17 (74%)
Age, median (min-max)	31 (24-50)
Norwegian as mother tongue	19 (83%)
Professional role as junior doctor, n (%)	22 (96%)
Years of work experience, median (min-max)	2.8 (0-17)
GENERAL PRACTITIONERS	n=25
Female, n (%)	8 (32%)
Age, median (min-max)	50 (35-71)
Norwegian as mother tongue	20 (80%)
Professional role as junior doctor, n (%)	5 (20%)
Years of work experience, median (min-max)	16 (1-44)

¹measured with MoCA Full assessment version 8.1, www.mocacognition.com, median score (range) ² According to medical records. ³Prescribed for regular use

S3. MADICI Decision tree



S4a. Coding sheet (identification of MADICI)

Line	Speaker	Transcript of audio-recorded consultation 1119/F [observation notes]	MADICI	MADICI-ID	Criteria 1	Criteria 2
3	GP	So you have been readmitted I see. I have received a discharge letter from the hospital.				
4	Patient	Yes, the pulse became too fast again, so... but not like it was when I was here with you that time.				
5	GP	No. And you were not that brilliant when you were readmitted now either.				
6	Patient	No.				
7	GP	You were heavy breathing and...let's see, only to see the conclusion of... from the discharge letter...[GP reads on the computer monitor] Yes, you received a couple of new medications.				
8	Patient	Yes [Laughs] <u>I have plenty of medications.</u>	1	1119/F/8m	medications	Patient's stance
9	GP	Yes, you have received two new ones, and then...because your potassium levels were low, and then you have also...				
10	Patient	I have it here too [patient shows discharge letter in paper version to the doctor]				
11	GP	Yes, and so you have... and so you have received...yes it is the same one that I have I believe. And so you have been given Burinex that is kind of a diuretic medicine. It is for heart failure.				
12	Patient	Yes, but she has given me two a day, and <u>that does not work you know</u> . No so ... <u>I take one</u> when I am home. And if I am doing something then <u>I cannot take it</u> .	1	1119/F/12m	"It" is an anaphoric reference to Burinex in line 11	I = patient is the agent, and the verb (take) is an action verb, Patient experience and stance (that does not work, if I'm doing something then I cannot take it)
13	GP	Yes but then...what it says here is 1 tablet in the morning and one at 1 pm. Two a day yes. But you... how many do you take now?				
14	Patient	<u>One</u>	1	1119/F/14m	"One" is an elliptical reference to "bumetanide tablets".	Response to doctor's question in line 13 referring to the patient (you) is the agent and the verb is an action verb (take)
15	GP	One. One in the morning?				
16	Patient	Yes, when I...you know I sleep abit long, so... <u>I take one Burinex</u> around noon. And <u>it works very well that one</u> , so...	1	1119/F/16m	Burinex (bumetanide), "it" and "that one" are anaphoric references to Burinex in the same MADICI	I = patient is the agent, and the verb (take) is an action verb, Patient experience (it works very well that one)
17	GP	Yes. How do you feel now?				

S4b. Coding sheet (characterisation of MADICI)

Line	Speaker	Transcript of audio-recorded consultation 1119/F [observation notes]	Reference to specific medication?	Which one?	Type 1	Type 2	Type 3	Type 4	Type 5	Type 6	Unprompted by doctor?
					(Information included =1, absent = 0)						
3	GP	So you have been readmitted I see. I have received a discharge letter from the hospital.									
4	Patient	Yes, the pulse became too fast again, so... but not like it was when I was here with you that time.									
5	GP	No. And you were not that brilliant when you were readmitted now either.									
6	Patient	No.									
7	GP	You were heavy breathing and...let's see, only to see the conclusion of... from the discharge letter...[GP reads on the computer monitor] Yes, you received a couple of new medications.									
8	Patient	Yes [Laughs] I have plenty of medications.	0		1	0	0	0	0	0	0
9	GP	Yes, you have received two new ones, and then...because your potassium levels were low, and then you have also...									
10	Patient	I have it here too [patient shows discharge letter in paper version to the doctor]									
11	GP	Yes, and so you have... and so you have received...yes it is the same one that I have I believe. And so you have been given Burinex that is kind of a diuretic medicine. It is for heart failure.									
12	Patient	Yes, but she has given me two a day, and that does not work you know. No so ...I take one when I am home. And if I am doing something then I cannot take it.	1	Bumetanide	1	0	0	0	1	0	1
13	GP	Yes but then...what it says here is 1 tablet in the morning and one at 1 pm. Two a day yes. But you... how many do you take now?									
14	Patient	One	1	Bumetanide	0	0	0	0	1	0	0
15	GP	One. One in the morning?									
16	Patient	Yes, when I...you know I sleep abit long, so... I take one Burinex around noon. And it works very well that one, so...	1	Bumetanide	0	0	0	0	1	0	0
17	GP	Yes. How do you feel now?									

Type 1: The MADICI provides information about patient's concerns, worries, fears, or a negative stance, Type 2: The MADICI indicated the patient is unsure or unable to name own medications, or cannot verify medications taken based on descriptions provided by doctor, Type 3: The MADICI provides information about relying on assistance from next of kin with medications to ensure correct dispensing, Type 4: The MADICI provides information about the patient not taking the first dose of a medication prescribed for regular use, Type 5: The MADICI provides information about the patient omitting, delaying, or taking too many doses of medication, and Type 6: The MADICI provides information about the patient intentionally discontinuing a medication that has not been deprescribed. Unprompted by doctor when provided (1) "out of the blue" or (2) when the patient stays on the same topic, but mid-utterance adds information and steers the conversation in a new directi

S5. Original quotes in Norwegian with translation to English

The following quotes have been used to present our results. Anaphoric references are included in [square brackets] and names removed for anonymity are replaced in italics. Transcripts are presented like this:

Original Norwegian version (normal font)

Word-for-word translation in English (bold font)

Quote 1: Bianca, GP-visit

«Nei ikke egentlig, for jeg tar nå de medisinene jeg skal ta til de riktige tidene. Og jeg prøver å holde det akkurat sånn innenfor... 40 minutter morgen og kveld da.»

“No, not really, because now I take the medications I should take at the correct times. And I try to keep it just within... within 40 minutes morning and evening.”

Quote 2: Daniel, GP-visit

«Så da kan jeg kutte kolesterolpillene [atorvastatin]?»

“So, then I can stop taking these cholesterol pills [atorvastatin]?”

Quote 3: Bianca, GP-visit

“Jeg tåler det [medisiner] tilsynelatende godt som jeg ser det selv da. Jeg ble ikke noe kvalm og jeg har ikke blitt noe dårlig av det [å starte med medisiner].»

“I tolerate it [medications] apparently well as I see it myself. I did not become nauseous, and I have not felt poorly due to it [starting with medications].”

Quote 4: Carl, GP-visit

«Ja, ja, jeg fortsetter å ta dem [diuretika]. Men jeg liker det ikke.»

“Yes yes, I will continue to take them [diuretic]. But I do not like it.”

Quote 5: Gabriel, GP-visit

«Ja men hun [sykehuslegen] har satt opp to [bumetanide] pr dag, og det går ikke vet du. Nei så det... jeg tar en [bumetanide] jeg når jeg er hjemme. Og hvis jeg skal noe så kan jeg ikke ta den [bumetanide].»

“Yes, but she [hospital doctor] has given me two [bumetanide] a day, and that does not work you know. No so... I take one [bumetanide] when I am home. And if I am doing something then I cannot take it [bumetanide].”

Quote 6: Carl, GP-visit

«Men det [å ta bumetanide] er ikke noe stas altså. Jeg får ikke gjort noe på formiddagen holdt jeg på å si.»

“But it [taking bumetanide] is no fun. I cannot get anything done before noon, I was about to say.”

Quote 7: Daniel, GP-visit

«Jo, jo, men ikke sant... jeg ser det, men hvis jeg er i normal tilstand og det er bivirkninger så vil jeg jo gjerne fjerne den [kolesterol senkende medisin].»

“But if I’m in a normal condition and there are side-effects then I would like to remove it [cholesterol lowering medication].”

Quote 8: Ken, First ward visit

“Jeg husker ikke. Det har vært veldig mye frem og tilbake med bytte ut gamle medisiner og få noen nye og litt sånn, så det har jeg ikke helt klarhet i.»

“I do not remember. It has been a lot back and forth with changing out old medications and getting some new ones and the like, so it is not clear to me.”

Quote 9: Martin, First ward visit

“Det er ikke akkurat greie navn på de der greiene da. Jeg vet at jeg har blodfortynnende og... jeg husker ikke... jeg bare tar dem jeg.»

“Its not exactly easy names on those things there. I know that I have an anticoagulant and...I do not remember...I just take those that I have.”

Quote 10: Eric, GP-visit

«Det er *navn venninne*... hun ordner opp [dosere medisiner] og legger opp i eskene etter den lista som vi har. Så hvis jeg har den Burinex-tabletten, at den står der, da tar jeg sikkert den.»

“It is *girlfriend’s name* ... she does it [dispensing medications] and puts into the boxes according to that list that we have. So if I have that bumetanide-tablet, that it is on that list there, then I probably take it.”

Quote 11: Benjamins daughter, GP-visit

“Det var det [dosere medisiner] jeg styrer med da, for jeg ringte hjemmesykepleien om de kunne komme og legge. Men de har jo ikke kapasitet, så jeg sitter jo med tunga i kjeften og legger.»

“That [dispensing in weekly pill organiser] is what I’m struggling with, because I called the home-nurse-team if they could come and dispense. But they did not have enough capacity, so I’m sitting now with the tongue in my mouth as I’m dispensing.”

Quote 12: Jane, GP-visit

«Jeg skulle egentlig begynne på tabletter for det [osteoporose] og, men jeg orker ikke... orker ikke flere tabletter.»

«I was supposed to start on tablets for that [osteoporosis] too, but I cannot stand...I cannot stand more tablets.”

Quote 13: Jane, GP-visit

«Aldri gått på det [reseptpliktige kalsium tabletter med D-vitaminer] jeg. Aldri gått på det, så det er feil.»

“Never been using those [prescription strength tablets with calcium with vitamin D], so that is wrong.”

Quote 14: David, GP-visit

«Pfh...Jeg glemmer det [å ta medisiner] vel en gang i uka.»

“Pfh... I forget it [taking medications] probably once a week.”

Quote 15: Brad, First ward visit

“Fordi at jeg slet med å sove sånn at jeg satt mye i sofaen hjemme og sov. Og da ble det at når jeg da stod opp av senga sånn i 3-4-tiden da var det ikke liksom tid for å ta den tabletten. Og så har jeg glemt av å ta den etterpå.»

“Because I struggled to fall asleep so that I sat a lot in the sofa at home and fell asleep. And then when I got out of bed 3 or 4 o’clock at night then it was kind of not the time to take that tablet. And then I forgot to take it afterwards.”

Quote 16: Carl, First ward visit

«Den har jeg sluttet med, for den [bumetanide]... jeg kunne ikke bruke den.»
“I’ve stopped taking that, because that one [bumetanide]... I could not use it.”

Quote 17: Babette, Discharge visit

«Den [chlorprotixene] tok jeg egentlig bort selv da jeg var på *øy i utlandet*.»
“That one [chlorprotixene] I took away myself when I was on the *island*.”

Excerpt from GP-visit (example of unprompted MADICI):

GP:

«Så har du fått en annen hjertesviktmedisin som heter [produsent navn på blodtrykksmedisin med valsartan], men den har du... ja den begynte du med også nå.»
“So now you have received another heart failure medication called [brand name of blood pressure medication with valsartan], but that one you have ...yes that one you have also started on now.”

Patient:

«Ja...Men disse vanndrivende pillene, når jeg tar dem om morgenen fra klokka 9 eller jeg kan jo stå opp 7 også for å ta dem. Hvor lenge virker de på dagen liksom? Jeg har følelsen av at de virker i hvert fall 4 til 5 timer. Er det riktig?»

“Yes, but these diuretic pills, when I take them in the morning from 9 o’clock ... or I can also get up at 7 also to take them. How long do they work during the day? I have a feeling that they work at least for 4 to 5 hours. Is that correct?”

S6. Detailed overview patient trajectories

Patient	Prescribed medications ²⁾		First heart ward visit in hospital (n=24)		Discharge visit from hospital (n=25)		Follow-up visit with GP (n=25)	
	At admission to hospital (n)	At discharge from hospital (n)	Duration ³⁾ (minutes)	MADICI (n)	Duration ³⁾ (minutes)	MADICI (n)	Duration ³⁾ (minutes)	MADICI (n)
<i>Carl</i>	6	7	19	35	12	4	30	24
<i>Barry</i>	0	5	19	2	15	0	20	4
<i>Bianca</i>	0	6	9	3	10	0	20	4
<i>Andrew</i>	9	9	15	1	5	1	22	4
<i>Eric</i>	12	12	8	3	15	3	15	3
<i>Christopher</i>	12	13	15	1	12	5	30	22
<i>Fred</i>	6	7	<i>not held</i>	<i>n/a</i>	10	2	19	5
<i>Alan</i>	14	14	10	4	5	3	17	8
<i>Gabriel</i>	10	11	10	3	14	5	18	14
<i>Brenda</i>	9	8	13	16	8	1	35	13
<i>Iris</i>	10	13	9	3	15	8	12	6
<i>Jane</i>	6	6	11	5	9	1	22	14
<i>Sally</i>	10	11	17	6	7	0	22	7
<i>Babette</i>	5	4	20	3	8	2	10	5
<i>Ken</i>	6	7	19	6	13	2	15	8
<i>Bob</i>	5	8	20	5	14	0	22	5
<i>Beatrice</i>	5	9	20	0	18	6	26	17
<i>Benjamin</i>	2	5	14	2	6	0	21	5
<i>Daniel</i>	4	7	22	0	16	2	14	18
<i>Dennis</i>	12	16	23	8	25	6	36	2
<i>David</i>	5	7	17	9	11	0	29	6
<i>Martin</i>	9	10	11	21	13	6	34	7
<i>Brad</i>	1	12	18	6	25	0	44	10
<i>Betty</i>	4	8	7	1	10	0	17	9
<i>Bruno</i>	6	8	6	0	9	0	21	7
TOTALS								
SUM	168	223	352	143	305	57	571	227
AVERAGE	6.72	8.92	14.67	5.96	12.2	2.28	22.84	9.08
MEDIAN	6.00	8.00	15.00	3.00	12.00	2.00	21.00	7.00
(min-max)	(0-25)	(5-16)	(6-23)	(0-35)	(5-25)	(0-8)	(10-44)	(2-24)

¹⁾Patients who received their first HF diagnosis within 3 months of the first ward visit were given pseudonyms beginning with the letter "B", ²⁾ Prescribed for regular use, ³⁾ Audio-recorded consultation time, to closest minute.

S7. Medications mentioned in “red-flag MADICI”

Name of active ingredient in medication linked to MADICI	Times medication was referred to¹⁾ (n)	Patients¹⁾ (n)
Bumetanide	37	8
Atorvastatin	10	4
Amiodarone	6	4
Bisoprolol	9	3
Ramipril	4	3
Metformin	7	2
Apixaban	4	2
Spironolactone	2	2

¹⁾Medications included in this table were referred to by more than 3 different patients in all 427 MADICI, followed by sorting for frequency in 235 “red-flag MADICI”.

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