

CML Patient Adherence Survey

Quantitative Questionnaire
ENGLISH



Programming notes and quota

Note to programmer: text for respondents is shown in **blue**.
Comments about section objectives are in **green** and will not be seen by respondents.
Questions are set out as follows:

QUESTION NUMBER. BASE

Question

(Coding instructions, question type)

Code for respondent	Code number	Go to question or close
Quota instructions (if required)		

Quotas

Aiming for a representative base across all markets, no set quotas, but needs to be monitored.



S1a. ALL RESPONDENTS

Language to conduct the interview. (Please select one answer only)

(Single code only; tick-box)

English	01	S1b
Francais	02	
Deutsch	03	
Italiano	04	
עברית	05	
Polski	06	
Nederlands	07	
Czechoslovakian	08	
Spanish	09	
Portuguese	10	
Russian	11	
Finnish	12	

INTRODUCTION TO SHOW TO RESPONDENTS

Welcome to the CML Patient Adherence Survey

The survey is run by the Leukemia Patient Advocates Foundation, a patient-run, non-profit foundation registered at Münzgraben 6, 3000 Bern, Switzerland. The survey has been developed by a working group of CML patient advocates and experts from across Europe and Israel, known as the European CML Workgroup, with unrestricted educational support from ARIAD, Bristol- Myers Squibb, Novartis and Pfizer.

This survey is run by patients for patients.

Adherence refers to the way patients take their medication.

Your answers to the questions in this survey will help us to better understand patient experiences with taking oral medications for CML. The results will help us develop tools and supportive materials that can help patients take their treatment as the CML doctor has prescribed and which is likely to improve treatment outcomes and quality of life.

[PN: Please Only Show the Below Sentence In The Online Web Study For France, Germany and Italy]

If you have already submitted a paper version of this questionnaire, please do not complete this online survey

CML Adherence Workgroup

Workgroup Chair:

Giora Sharf

Director of the Israeli CML Patients Organisation (Israel)

<http://www.cml.org.il>



Workgroup Members:
Felice Bombaci
Chairman of the Gruppo
AIL Pazienti Leucemia Mieloide Cronica (Italy)
<http://www.lmconline.it>

Mina Daban
President of LMC France (France)
<http://www.lmc-france.fr>

Tony Gavin
Director of Campaigning and Advocacy at Leukaemia CARE (UK)
<http://www.leukaemiacare.org.uk>

Jan de Jong
Member of the Board of Stichting Contactgroep Leukemie (Netherlands)
<http://www.leukemie.nfk.nl/>

Euzebiusz Dziwinski
Vice President of the Nationwide Association for CML Patients Aid Poland
<http://www.spbs.com.pl>

Jana Pelouchova
Founder and Chair - Diagnoza CML Czech Republic
<http://www.diagnoza-cml.cz>

Jan Geissler
Executive Director - Leukamie - Online Germany
<http://www.leukaemie-online.de>

Dr. Fabio Efficace
Head Health Outcomes Research Unit of the Italian Group for Adult Hematologic
Diseases - GIMEMA Data Centre (Italy)
<http://www.gimema.org>

Dr. Joëlle Guilhot
Biostatistics, INSERM CIC 0802, University Hospital of Poitiers (France)



Screener section (Estimated 1 minute)

S1b. ALL RESPONDENTS

What country do you live in? (Please select one answer only)

(Single code only; tick-box)

Programmer instructions: drop down menu if possible. Please keep order of countries alphabetical for all languages

Afghanistan	01	S2
Albania	02	
Algeria	03	
Andorra	04	
Angola	05	
Antigua & Barbuda	06	
Argentina	07	
Armenia	08	
Australia	09	
Austria	10	
Azerbaijan	11	
Bahamas, The	12	
Bahrain	13	
Bangladesh	14	
Barbados	15	
Belarus	16	
Belgium	17	
Belize	18	
Benin	19	
Bhutan	20	
Bolivia	21	
Bosnia and Herzegovina	22	
Botswana	23	
Brazil	24	
Brunei	25	
Bulgaria	26	
Burkina Faso	27	
Burma	28	
Burundi	29	
Costa Rica	30	
Cote d'Ivoire	31	
Croatia	32	
Cuba	33	
Cyprus	34	
Czech Republic	35	
Democratic People's Republic of Korea	36	



Democratic Republic of the Congo	37	S2
Denmark	38	
Djibouti	39	
Dominica	40	
Dominican Republic	41	
Ecuador	42	
Egypt	43	
El Salvador	44	
Equatorial Guinea	45	
Eritrea	46	
Estonia	47	
Ethiopia	48	
Fiji	49	
Finland	50	
France	51	
Gabon	52	
Gambia	53	
Georgia	54	
Germany	55	
Ghana	56	
Greece	57	
Grenada	58	
Guatemala	59	
Guinea	60	
Guinea-Bissau	61	
Guyana	62	
Haiti	63	
Honduras	64	
Hungary	65	
Iceland	66	
India	67	
Indonesia	68	
Iran (Islamic Republic of)	69	
Iraq	70	
Ireland	71	
Israel	72	
Italy	73	
Jamaica	74	
Japan	75	
Jordan	76	
Kazakhstan	77	
Kenya	78	
Kiribati	79	



Kuwait	80	S2
Kyrgyzstan	81	
Lao People's Democratic Republic	82	
Latvia	83	
Lebanon	84	
Lesotho	85	
Liberia	86	
Libyan Arab Jamahiriya	87	
Lithuania	88	
Luxembourg	89	
Madagascar	90	
Malawi	91	
Malaysia	92	
Maldives	93	
Mali	94	
Malta	95	
Marshall Islands	96	
Mauritania	97	
Mauritius	98	
Mexico	99	
Micronesia (Federated States of)	100	
Monaco	101	
Mongolia	102	
Montenegro	103	
Morocco	104	
Mozambique	105	
Myanmar	106	
Namibia	107	
Nauru	108	
Nepal	109	
Netherlands	110	
New Zealand	111	
Nicaragua	112	
Niger	113	
Nigeria	114	
Niue	115	
Norway	116	
Oman	117	
Pakistan	118	
Palau	119	
Panama	120	
Papua New Guinea	121	
Paraguay	122	



Peru	123	
Philippines	124	
Poland	125	
Portugal	126	
Qatar	127	
Republic of Korea	128	
Republic of Moldova	129	
Romania	130	
Russian Federation	131	
Rwanda	132	
Saint Kitts and Nevis	133	
Saint Lucia	134	
Saint Vincent and the Grenadines	135	
Samoa	136	
San Marino	137	
Sao Tome and Principe	138	
Saudi Arabia	139	
Senegal	140	
Serbia	141	
Seychelles	142	
Sierra Leone	143	
Singapore	144	
Slovakia	145	
Slovenia	146	
Solomon Islands	147	
Somalia	148	
South Africa	149	
Spain	150	
Sri Lanka	151	
Sudan	152	
Suriname	153	
Swaziland	154	
Sweden	155	
Switzerland	156	
Syrian Arab Republic	157	
Tajikistan	158	
Thailand	159	
The former Yugoslav Republic of Macedonia	160	
Timor-Leste	161	
Togo	162	
Tonga	163	
Trinidad and Tobago	164	
Tunisia	165	



Turkey	166	S2
Turkmenistan	167	
Tuvalu	168	
Uganda	169	
Ukraine	170	
United Arab Emirates	171	
United Kingdom	172	
United Republic of Tanzania	173	
United States of America	174	
Uruguay	175	
Uzbekistan	176	
Vanuatu	177	
Venezuela (Bolivarian Republic of)	178	
Viet Nam	179	
Yemen	180	
Zambia	181	
Zimbabwe	182	
Other	183	
See quota instructions for base in each market.		



S2. ALL RESPONDENTS

Are you a Chronic Myeloid Leukaemia (CML) patient? (Please select one answer only)

(Single code only; tick box)

Yes	01	S3
No	02	CLOSE

S3. ALL RESPONDENTS

Do you take an oral medication to treat your CML? (Please select one answer only)

(Single code only; tick-box)

Yes	01	S4
No	02	CLOSE

S4. ALL RESPONDENTS

Please take a few moments to read the following:

The key aim of this research is to add insight into the factors influencing the way CML patients take their medication. The outputs of this research may be published by the leukaemia patient advocates network for educational purposes and only at a summarised level and/or using anonymous quotes.

To participate in this interview, you must be a Chronic Myeloid Leukaemia (CML) patient (who is at least 18 years old) currently receiving oral medication for your CML.

Any information that you disclose will be treated in the strictest confidence and the results of the research will be summarised to provide an overall picture of attitudes to the areas being covered in this survey. No answers will be attributed to you as an individual.

You have the right to withdraw from the survey at any time and to withhold information as you see fit.

By answering 'yes' to the question below, I confirm that I have read, understood and accept the points above.

Are you happy to proceed on this basis)? (Please select one answer only)

(Single code only; tick-box)

Yes	01	SEC. A
No	02	CLOSE

Section A: Demographics (Estimated 2 minutes)

Objective:

- To gather information on the demographics of respondents

INTRO A (i) SHOW TO ALL RESPONDENTS

In this first section we would like to find out a little bit about you.

A1. ALL RESPONDENTS

How old are you? (Please insert your year of birth below.)

(Numeric answer, range between 1900 and 2000)

YYYY (Allow respondent to write in answer; close if answer more than 1994)	01	A2
--	----	----

A2. ALL RESPONDENTS

What is your gender? (Please select one answer only)

(Single code only; tick-box)

Male	01	A3
Female	02	

A3. ALL RESPONDENTS

What best describes your highest level of education? (Please select one answer only)

(Single code only; tick-box)

Eight (8) years of education or less (IN FINLAND SHOW 9 years) (IN GERMANY SHOW Ten (10) or less years of schooling (primary school, secondary school))	01	
Between 9 to 12 years of education (IN FINLAND SHOW 10-12 years) (IN GERMANY SHOW Between 11 and 13 years of school (high school))	02	
Higher level education (more than 12 years) (IN GERMANY SHOW Higher education degrees (more than 13 years, college degree))	03	

A4. ALL RESPONDENTS

What are your caregiving arrangements? (Please select all that apply.)

(Multi-code; tick-box, 03 cannot be coded with another option)

I live with a spouse, partner and/or family member	01	A5
I live with a professional carer	02	
I live alone	03	
Other	04	

A5. ALL RESPONDENTS

Do you personally pay (from your "own pocket") for your CML medication? (Please select one answer only)

(Single code only; tick-box)

Not at all	01	A6a
Yes, fully	02	
Yes, partially, on average I pay more than €50 EUROS per month	03	
Yes, partially, on average I pay less than €50 EUROS (or equivalent) per month	04	



No - I have a medical exemption (MedEx) certificate (SHOW CODE 05 IN UK ONLY)	05	
---	----	--

A6a. ALL RESPONDENTS

How far do you travel (round trip) to get your CML medication (to specify, the question means the pills, not the prescription)? (Please select one answer only)

(Single code only; tick-box)

I do not need to travel because I get my medication by mail	01	Sec. B
I do not need to travel because someone delivers my medication to me	02	Sec. B
Under 5 km	03	A6b
Between 5 to 15 km	04	A6b
Over 15km up to 25 km	05	A6b
Over 25km up to 50 km	06	A6b
Over 50km up to 75 km	07	A6b
Over 75 km	08	A6b
I don't know	09	A6b

A6b. ALL RESPONDENTS WHO DON'T CODE 01 OR 02 AT A6a

How often do you travel to get your CML medication (to get the pills, not the prescription)? (Please select one answer only)

(Single code only; tick-box)

More than once a month	01	A6c
Monthly	02	
Every 2 to 3 months	03	
Every 4 to 6 months	04	
Less frequently than every 6 months	05	

A6c. ALL RESPONDENTS WHO DON'T CODE 01 OR 02 AT A6a

And where do you get your medication from usually? (Please select one answer only)

(Single code only; tick-box)

The hospital pharmacy	01	Sec. B
A community based pharmacy	02	
During consultation with the CML doctor treating my CML	03	
Other	04	



Section B: CML Diagnosis and treatment (Estimated 3 minutes)

Objective:

- To understand about the diagnosis and treatment of the patient's CML, numbers of patients on each treatment, length of time on therapy, etc.

INTRO B (i) SHOW TO ALL RESPONDENTS This section focuses on the diagnosis and treatment of your CML.

B1. ALL RESPONDENTS

What phase of CML are you in? (Please select one answer only)

(Single code only; tick-box)

Chronic phase	01	B2
Accelerated phase	02	
Blast phase	03	
I don't know	04	

B2. ALL RESPONDENTS

When were you diagnosed with CML? (Please write in the year below)

(Numeric answer; range 1985 - 2012)

YYYY (Allow respondent to write in answer, cannot be earlier than birthday at A1)	01	B3a
---	----	-----

B3a. ALL RESPONDENTS

Which medication do you take for your CML currently? (Please select one answer only)

(Single code only; tick-box)

Glivec® (also known as imatinib)	01	B3b
Tasigna® (also known as nilotinib)	02	
Sprycel® (also known as dasatinib)	03	
bosutinib	04	
ponatinib	05	
A pill form of a tyrosine kinase inhibitor (TKI), but I do not know the name	06	
Other / none of the above	07	
I don't know / cannot recall	08	

B3b. ALL RESPONDENTS

Are you taking your oral medication in combination with Interferon and/ or hydroxyurea (also known as Droxia/Hydrea/Litalir/Onco-Carbide)? (Please select one answer only)

(Single code only; tick-box)

Yes	01	B3c
No	02	
I don't know / I cannot recall	03	

B3c. ALL RESPONDENTS



Are you currently taking part in a clinical trial? (Please select one answer only)
 (Single code only; tick-box)

Yes	01	B4a
No	02	
I don't know / I cannot recall	03	

B4a. ALL RESPONDENTS

How many times a day do you take your CML medication? (Please select one answer only)
 (Single code only; tick-box)

Once (1x) a day	01	B4b
Twice (2x) a day	02	
Three times (3x) a day	03	
Four times (4x) a day	04	
Other	05	

B4b. ALL RESPONDENTS

When during the day do you usually take your CML medication? (Please select all that apply)
 (Multi code; tick-box)

Morning	01	B5
Midday	02	
Evening	03	
More than once a day	04	
Other	05	

B5. ALL RESPONDENTS

How long have you been taking this drug as your CML medication? (Please select one answer only)

(Single code only; tick-box)

Less than 6 months	01	B6
Between 6 months and up to a 1 year	02	
Over 1 and up to 3 years	03	
Over 3 and up to 5 years	04	
Over 5 and up to 10 years	05	
Over 10 years	06	

B6. ALL RESPONDENTS

What CML treatments, if any, did you have before you began to take the one you are currently taking? (Please select all that apply)

(Multi-code; tick-box; only show answers that were not selected at B3a)

I didn't have any CML treatments before this one	01	B7
Glivec® (also known as imatinib)	02	
Tasigna® (also known as nilotinib)	03	
Sprycel® (also known as dasatinib)	04	
bosutinib	05	
ponatinib	06	
A tyrosine kinase inhibitor (TKI), but I do not know the name	07	
Interferon	08	



Hydroxyurea (also known as Droxia/Hydrea/Litalir/Onco-Carbide)	09	
I had a bone marrow / stem cell transplant	10	
None of the above / other	11	
I don't know / cannot recall	12	

B7. ALL RESPONDENTS

In addition to your CML medication, how many other medications do you take every day for diseases other than CML (e.g. diabetes or hypertension medications)? (Please select one answer only)

(Single code only; tick-box)

1 to 2 other medications	01	Sec. C
3 to 4 other medications	02	
5 to 6 other medications	03	
More than 6 other medications	04	
I do not take any other medications	05	



Section C: CML Treatment Adherence (Estimated 7 minutes)

Objective:

- To measure the attitudes of the patients toward CML adherence

INTRO C (i) SHOW TO ALL RESPONDENTS

As you answer the following questions, please think about how easy it is to take your medication or challenges you may face when taking your medication exactly as prescribed by the CML doctor.

C1. ALL RESPONDENTS

In general, to what extent do you think you are able to stick to your CML therapy schedules and dosage, as prescribed by your CML doctor? (Please use the scale below to indicate the extent to which you stick to your CML therapy schedules and dosing with 1 meaning rarely and 5 meaning you always stick to the schedules and dosing)

(Single code; tick box)

I <u>rarely</u> take my CML medicine exactly as prescribed	01	02	03	04	05	I <u>always</u> take my CML medicine exactly as prescribed	C2a
--	----	----	----	----	----	--	-----

C2a. ALL RESPONDENTS

Patients sometimes are not able to take their medication as prescribed. In the last month, have you missed a dose accidentally or due to circumstances that were outside of your control? (Please select one answer only)

(Single code only; tick-box)

Yes	01	C2b
No	02	C2c
I don't know	03	C2c

C2b. ALL RESPONDENTS WHO CODED 01 AT C2a

How many doses did you miss in the last month? (Please write in the number below)

(Numeric answer, range between >0 and ≤60)

	01	C2d
--	----	-----

C2c. ALL RESPONDENTS WHO CODED 02 OR 03 AT C2a

In the last year, have you missed a dose accidentally or due to circumstances that were outside of your control? (Please select one answer only)

(Single code only; tick-box)

Yes	01	C2cc
No	02	C4a
I don't know	03	C4a



C2cc. ALL RESPONDENTS WHO CODE 01 AT C2c

How many doses did you miss in the last year? (Please write in the number below)

(Numeric answer, range between >0 and ≤180)

	01	C2d
--	----	-----

C2d. ALL RESPONDENTS WHO CODE 1 AT C2A OR CODE 1 AT C2C

Which circumstances led to a missed dose of your medication? (Choose all that apply.)

(Multi-code; tick-box)

Programmer instruction: randomise order the circumstances are shown, keep code 12, 13 and 14 at the bottom

I forgot to take the medication	01	C3
The dosage schedule is too complicated	02	
I couldn't swallow the pill	03	
The medication wasn't ready at the pharmacy	04	
I ran out of medication	05	
My reminder device failed and I forgot	07	
My daily routine was interrupted	08	
I fell asleep before taking it	09	
I was travelling	10	
I was too ill	11	
I don't know / I cannot recall	12	
Other	13	
Not applicable	14	

C3. ALL RESPONDENTS WHO CODE 1 AT C2A OR CODE 1 AT C2C

For doses that you have missed accidentally or due to circumstances outside of your control, which are you more likely to miss? (Choose all that apply.)

(Multi-code; tick-box)

Morning dose	01	C4a
Afternoon dose	02	
Evening dose	03	
Doses on weekdays	04	
Doses on weekends	05	
Doses during holidays	06	
Doses when I am travelling	07	
I don't know	08	
Not applicable	09	

C4a. ALL RESPONDENTS

Patients sometimes make a conscious decision to miss a dose of medication. In the last month, have you decided to miss a dose? (Please select one answer only)

(Single code only; tick-box)

Yes	01	C5
No	02	C4b



C4b. ALL RESPONDENTS WHO CODE 02 AT C4a

In the last year, have you decided to miss a dose? (Please select one answer only)

(Single code only; tick-box)

Yes	01	C5
No	02	C7a

C5. ALL RESPONDENTS ALL RESPONDENTS WHO CODE 1 AT C4a OR CODE 1 AT C4b

Why did you decide to miss a dose of your medication? (Choose all that apply.)

(Multi-code; tick-box)

Programmer instruction: randomise order the treatments are shown, keep code 14 and 15 at the bottom

To save money	01	C7a
To reduce side effects	02	C6
I was feeling better	03	C7a
It interfered with my travel plans or holiday	04	
My tests showed my CML was under control	05	
My CML doctor told me I could miss a dose	06	
My friend/ partner said I could miss a dose	07	
I didn't want to be reminded of my CML	08	
It interfered with my work schedule	09	
I was feeling down	10	
I wasn't feeling well	11	
I was attending a special occasion	12	
I wanted to go out/socialise	13	
Other	14	
Not applicable	15	



C6. ALL RESPONDENTS WHO SELECT C5 CODE 02

Which side effect(s) were you hoping to avoid by intentionally missing one or more doses of your medication? (Please choose all that apply.)

(Multi-code; tick-box)

Programmer instruction: randomise order the statements are shown, keep code 19 at the bottom

Tiredness / weakness	01	C7a
Nausea	02	
Muscle cramps / muscle pain	03	
Headaches	04	
Skin rash or itching sensation	05	
Loss of focus or concentration	06	
Change in mood	07	
Diarrhoea / gastrointestinal issues	08	
Hair loss	09	
Bone pain	10	
Vomiting	11	
Fever	12	
Shortness of breath or cough	13	
Constipation	14	
Anxiety	15	
Dizziness	16	
Weight gain	17	
Loss of appetite	18	
Other	19	

C7a. ALL RESPONDENTS

Have you ever decided to take a break from your CML medication without talking to your CML doctor or nurse? (Please select one answer only)

(Single code only; tick-box)

Yes	01	C7b
No	02	C8

C7b. RESPONDENTS WHO CODE 01 AT C7a

Please tell us the number of days that you took off your CML medication. (Please write your answer in the space below)

(Numeric answer, range between 001 and 100)

Number of days ___	01	C8
--------------------	----	----

C8 ALL RESPONDENTS

This next question asks about your general attitudes towards CML treatment.

When thinking about your CML medication, please indicate the extent to which you agree with each of the following statements? (Please indicate for each item below on a scale of 1-7 where 1=strongly disagree and 7=strongly agree)

(Radio buttons - 1 to 7 1=Strongly Disagree; 7= Strongly Agree, anchor text to codes 1 and 7, randomise order the statements are shown)



	Strongly Disagree 1	2	3	4	5	6	Strongly Agree 7	Don't know / Not applicable		
It is ok to miss a few doses of my CML medication every now and then	01	02	03	04	05	06	07	08	01	Sec. D
I worry if I miss a dose of my CML medication	01	02	03	04	05	06	07	08	02	
I have been told I need to take every dose of my CML treatment or the treatment may not work	01	02	03	04	05	06	07	08	03	
My health depends on my CML medication	01	02	03	04	05	06	07	08	04	
Having to take my CML medication worries me	01	02	03	04	05	06	07	08	05	
I worry about the long term effects of my CML medication	01	02	03	04	05	06	07	08	06	
My CML medication disrupts my life	01	02	03	04	05	06	07	08	07	
I find it difficult to swallow my CML medication	01	02	03	04	05	06	07	08	08	
I find it difficult to open / close the CML medication packages	01	02	03	04	05	06	07	08	09	
My CML medication impacts my social life	01	02	03	04	05	06	07	08	10	
My CML medication impacts my work life	01	02	03	04	05	06	07	08	11	



Section D: Interaction with the CML doctor treating you for CML (Estimated 7 minutes)

Objective:

- To measure how CML patients interact with their CML doctors

INTRO D(i) SHOW TO ALL RESPONDENTS

As you answer the following questions, please think about the way you interact with the CML doctor treating you for CML.

D1a. ALL RESPONDENTS

How many times have you seen your CML doctor about your CML in the past 6 months? (Please select one response only)

(Single code, tick-box)

Not at all	01	D1b
Once or twice	02	
Three or four times	03	
More than four times	04	
I don't know	05	

D1b. ALL RESPONDENTS

How satisfied are you with the information you receive from your CML doctor about CML and how it can impact your life? (Please select one answer only.)

(Single code, tick-box)

Very satisfied	01	D1c
Somewhat satisfied	02	
Somewhat dissatisfied	03	
Not satisfied at all	04	

D1c. ALL RESPONDENTS

How often do you talk to your CML doctor about your medication side effects? (Please select one response only)

(Single code, tick-box)

We talk about it at almost every visit	01	D2
We talk about it only if I ask for it	02	
We almost never discuss it	03	

D2. ALL RESPONDENTS

How approachable do you find your CML doctor is in terms of discussing the challenges you may be facing in taking your CML medication? (Please select one response only)

(Single code, tick-box)

My CML doctor is not very approachable	01	D3
My CML doctor is somewhat approachable	02	
My CML doctor is very approachable	03	



D3. ALL RESPONDENTS

How satisfied are you with the way your CML doctor helps you manage your side effects?
(Please select one response only)

(Single code, tick-box)

Very satisfied	01	D4
Somewhat satisfied	02	
Somewhat dissatisfied	03	
Not satisfied at all	04	
I don't have any side effects	05	

D4. ALL RESPONDENTS

Have you ever talked to your CML doctor, nurse or pharmacist about what might happen if you miss a dose of your CML medication? (Please select one response only)

(Single code, tick-box)

Yes	01	D5a
No	02	
I don't recall	03	

D5a. ALL RESPONDENTS

Would you tell your CML doctor if you missed your CML medication accidentally or due to circumstances beyond your control? (Please select one response only)

(Single code, tick-box)

Yes, always	01	D5b
Yes, sometimes	02	
No	03	
I don't know	04	

D5b. ALL RESPONDENTS

Would you tell your CML doctor if you decided to miss a dose(s) of your CML medication? (Please select one response only)

(Single code, tick-box)

Yes, always	01	D6
Yes, sometimes	02	
No	03	
I don't know	04	

D6. ALL RESPONDENTS

What do you think would happen if you miss one or more doses of your CML medication within the space of a month? (Choose all that apply)

(Multi-code, tick-box)

I would feel worse	01	D7
I would feel better	02	
There is a higher chance of CML progression or recurrence	03	
There is a higher chance of treatment resistance	04	
I am more likely to die from the disease	05	
Nothing will happen	06	
Other (please specify) (Open ended response)	07	



D7. ALL RESPONDENTS

Please rank the top three (3) people you are most comfortable talking about your CML medication and side effects with 1 being the person you are most comfortable speaking to about your medication (Choose three of the options and rank 1st, 2nd and 3rd)

(Numeric answers of 1, 2 and 3)

My CML doctor	INSERT 1 to 3	D8
The specialist hospital nurse	INSERT 1 to 3	
The pharmacist	INSERT 1 to 3	
A friend or relative	INSERT 1 to 3	
A psychologist or psycho- oncologist	INSERT 1 to 3	
CML patient association	INSERT 1 to 3	
A GP (general practitioner)	INSERT 1 to 3	
Other	INSERT 1 to 3	

D8. ALL RESPONDENTS

Since you have been diagnosed with CML, have you ever talked with a psychologist or psycho-oncologist? (Please select one response only)

(Single code, tick-box)

Yes	01	D9
No	02	D10

D9. ALL RESPONDENTS WHO CODE 01 AT D8

Which topics did you talk about with your psychologist or psycho-oncologist? (Choose all that apply.)

(Multi-code, tick-box)

Dealing with the disease in general	01	D10
Dealing with side effects	02	
Impact of the disease on my quality of life	03	
Other	04	

D10. ALL RESPONDENTS

Do you get information or support from a patient association or discussion group? (Please select one response only)

(Single code, tick-box)

Yes	01	D11
No	02	D12
I don't recall	03	



D11. ALL RESPONDENTS WHO CODE 01 AT D10

Which organisation(s) do you seek support from? (Please write in your answer below)

OPEN QUESTION	01	D12
---------------	----	-----

D12. ALL RESPONDENTS

Which of the following sources have you used to gather information about your CML treatment in the past 3 months? (Choose all that apply).

(Multi-code, tick-box - unless code 09, then it is single code only)

A CML doctor physician	01	Sec. E
A GP / primary care doctor / pharmacist or other healthcare professional	02	
Family / friends	03	
Newspaper / magazine articles	04	
The internet	05	
Brochures in doctors' offices	06	
Other patients / patient support program	07	
Other - please specify (Open ended response)	08	
I have not spoken to anyone or found any information / advice about my condition	09	



Section E: Adherence Tools (Estimated 1 minute)

Objective:

- To test tools that could help CML patient adherence

E1. ALL RESPONDENTS

In order to remember to take their medication, patients sometimes try to follow a routine. Does having a daily routine help you remember to take your medication? (Please select one response only)

(Single code, tick-box)

Routine helps greatly	01	E2
Routine helps moderately	02	
Routine helps little	03	
Routine does not help	04	
I do not have a routine	05	

E2.

Below is a list of tools that could help you to remember to take your CML medication. For each item, please indicate whether you already use such a tool, or if you would use the tool if it were available. (Please select one response per row.)

(Single code per row, tick-box)

Programmer instruction: randomise order the statements are shown

	I use this tool already	I would use this tool if it were available	I would not use this tool		E3
Alarm clock reminders	01	02	03	01	
Electronic reminders via mobile phones such as SMS or alarms	01	02	03	02	
Phone call reminders	01	02	03	03	
Email reminders	01	02	03	04	
Reminders from doctors or nurses during appointments	01	02	03	05	
Reminders from family members	01	02	03	06	
Refrigerator magnet reminders	01	02	03	07	
Medication box/pill dispenser	01	02	03	08	



Smart phone / mobile applications	01	02	03	09	
---	----	----	----	----	--

E3. ALL RESPONDENTS

Do you have any suggestions for tools or routines that could help patients remember to take their CML medication? Please include routines that you use for taking your CML medication. (Please write in your suggestions in as much detail as possible below)

(Open ended response)		Sec. F
-----------------------	--	--------

Section F: Adherence Scale

INTRO E (i) SHOW TO ALL RESPONDENTS



We would like you to answer two final questions about adherence. You may feel as though you have already covered similar points in previous questions, however the answers you give here are still important for this survey.

F1. Please answer ‘yes’ or ‘no’ to each question based on your personal experience with your CML medication.

(Single code per statement; tick box)

	Yes	No	
Do you sometimes forget to take your CML medication?	01	02	F2
People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past two weeks, were there any days when you did not take your CML medicine?	01	02	
Have you ever cut back or stopped taking your medication without telling your doctor, because you felt worse when you took it?	01	02	
When you travel or leave home, do you sometimes forget to bring along your CML medication?	01	02	
Did you take your CML medicine yesterday?	01	02	
When you feel like your CML is under control, do you sometimes stop taking your medicine?	01	02	
Taking medication every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your CML treatment plan?	01	02	

F2. How often do you have difficulty remembering to take all your medications? (Please select one answer only).

(Single code only; tick box)

Never/Rarely	01	F3
Once in a while	02	
Sometimes	03	
Usually	04	
All the time	05	

Thank you very much for your time and willingness to participate our study.

F3. SCRIPTOR: PLEASE RECORD THE DATE THE SURVEY WAS COMPLETED