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GAMIAN-Europe

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Gamian-Europe

Presentation:

GAMIAN-Europe ¹ was established in 1998 as a representative coalition of patient organisations. Putting the patient at the centre of all issues of the EU healthcare debate, the organisation aims to bring together and support the development and policy influencing capacity of local, regional and national organizations active in the field of mental health.

Patients can and should play an effective and complementary role in developing positive and proactive policies and other initiatives with an impact on mental health issues. GAMIAN-Europe, as an informed and effective advocate, is seeking to become a powerful and trusted point of reference for the main EU institutions and other organizations and stakeholders seeking the views of patients.

GAMIAN-Europe's main objectives:

Advocacy

- Act as the voice for patients, both at EU as well as at national level, and demonstrate that this voice is useful as well as indispensable
- Ensure that patients are at the centre of all aspects of healthcare provision
- Work to improve the availability, accessibility, and quality of treatment for all mental health problems

Information and education

- Improve the provision, reliability and quality of information on mental health problems for patients as well as the general public
- Assist in improving the training, education and understanding of mental illness of health and other professionals

Stigma and discrimination

Increase awareness, knowledge and understanding of mental health problems

President: Pedro Montellano (Portugal);Immediate Past President: Dolores Gauci (Malta)

Vice-President: Flavio Prata (Italy), Secretary General: Rebecca Müller (Belgium), Treasurer: Hilkka Kärkkäinen (Finland)

Counselors: Aikaterini Nomidou (Greece), Aušra Mikulskienė (Lithuania) Bert Aben (Netherlands), John Bowis (United Kingdom), Raluca Nica (Romania),

Board of Directors:

• Help reduce stigma, prejudice, and ignorance in relation to mental health problems and fight discrimination

Patient's rights

• Focus on the development and enforcement of rights for persons affected by mental health problems, e.g. access to appropriate treatment

Cooperation, partnerships and capacity building

 Enable patient groups to collaborate with health professionals, policy makers, academics, and industry

GAMIAN-Europe's activities:

In order to reach these aims, GAMIAN-Europe

- provides information and support to member organisations by means of educational seminars, conventions, a regular EU newsletter, handbooks on specific mental illnesses, and an up-to-date and accessible website.
- facilitates an open and inclusive pan-European dialogue among patient organisations and other interested bodies to exchange information and ideas.
- shares experience and examples of good practice to strengthen the role and voice of patient organizations and effective input in EU and national policy development.
- forms active partnerships and cooperation with other stakeholders, e.g. the media, organizations (local, regional, national, European and academic institutions), employers and trade unions, the pharmaceutical industry, government and regulatory bodies and insurers with a view to
 - securing the best possible treatment for patients with a mental illness and at the earliest possible opportunity
 - supporting the development of health/mental health policies which take account of the views of patients

Gamian Questionnaires, an user run initiative

GAMIAN-Europe wishes to contribute to an open and innovative reflection process, in order to advocate the need to address health in a holistic fashion and the development of care and support facilities and services for people with mental health problems.

To this effect, GAMIAN-Europe stimulate international cooperation and awareness raising on important topics, for instance by means of the European Interest Group on Mental Health, Well-being and Brains Disorders, to which GAMIAN-Europe provides the secretariat.

Aiming to speak up for patients, GAMIAN-Europe organizes since 2006 regular consultations of its membership (through national patient associations in most European countries:

Stigma Survey - project developed by GAMIAN Europe in 2006.

In 2006 GAMIAN-Europe undertook an extensive pan-European survey involving twenty countries across geographical Europe with a meaningful spread to involve countries from Eastern, Central, Western, Northern and Southern Europe utilising our extensive organisation's membership in those countries.

In 2010 the questionnaire was submitted again, to see if there has been any evolution in the last 5 years.

The results were presented at the EU conference on stigma in Lisbon (November 2010) and at the MEP interest group (3rd May 2011)

In 2011 a second survey was set up on the physical health problems of people suffering from mental health problems

In 2012 a questionnaire on adherence to treatment will be conducted.

Gamian-Europe and the physical health problems of people suffering from mental health problems

Some facts

As stated in the Mental and Physical health Charter, developed by the Physical and Mental Health Platform², people with enduring mental health problems are more likely to develop physical health problems than the general population. Conversely, poor physical health can have a negative effect on mental health.

For instance, people with mental illnesses:

- have a two to threefold increased risk of death compared to persons of the same age and gender in the general population.
- die on average 20 years younger than the general population, with cardiovascular disease being the leading cause.
- are more likely to develop a range of chronic respiratory conditions including chronic obstructive pulmonary disease (COPD), chronic bronchitis and asthma;
- have a higher risk of developing some cancers; people living with cancer have higher risks of developing depression;
- run a higher risk of developing heart disease. About 1 in 3 people who have a heart attack also experience depression;
- are 2 to 3 times more likely to develop diabetes and other cardiovascular risk factors.

In addition, stigma remains a major problem: almost two thirds of all people with mental disorders do not seek treatment, largely because of stigma.

Apart from the obvious burden and impact in individuals, mental and physical health problems have substantial costs to society. The Mental and Physical health Charter states that the costs of poor mental health alone in the EU have been estimated at €436 billion each year. The additional costs of physical health problems in mentally ill may increase this figure by as much as 70%.

There are also positive interactions between mental and physical health: mental well-being supports good physical health and vice versa.

² The Physical and Mental Health Platform was formed in April 2008 to provide a forum for dialogue, raise awareness put forward policy recommendations for action. It is a multi-stakeholder initiative gathering together advocacy groups and experts from across disease areas and countries.

A survey on Mental and Physical health. The Physical and Mental Health Online Questionnaire.

In 2011 GAMIAN-Europe has conducted a survey on the physical health of people living with mental illness

For Gamian-Europe it is important to hear from patients what their true experience is.

The main aim of this pan-European survey is to assess patients experience of healthcare systems in different countries. In particular the survey is looking at the interlinks between mental and physical health and the impact on patient lives.

The results of this survey will be submitted to National and EU policy-makers in the aim to advocate for a better integration of mental and physical healthcare systems to improve health outcomes of people living with mental disorders.

Funding

This study was conducted with assistance of Hill&Knowlton and financed by BMS.

Procedure

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- The questionnaire was edited by a steering committee of patient representatives³ and academics: David McDaid LSE) & Marc De Hert (University Leuven). As representatives of BMS (the funder) Mrs Van Dooselaere and Dr Wally Landsberg participated.
- No language barrier: everyone can respond in his or her own language Survey packs ware translated in 20 languages (using forward-back translation approach)
- Survey was put online on the Gamian site and on the Gamian Facebook, Twitter and Linkedin pages Both online and printed version, accessible at the GAMIAN website
- Active from November 2011 until April 2012
- 1156 Responses from 30 countries (Q3)

Old EU (Belgium, Denmark, Finland, France, Greece, Italy, Portugal, Spain, Sweden, The Netherlands, UK)	422
New EU (Cyprus, Latvia, Poland, Hungary, Czech Republic, Romania, Malta, Lithuania, Slovenia)	413
Europe Not EU (Croatia, Israel, Turkey, Russia)	313
Not Europe (Pakistan, Kenya, Uganda, Un Arab , Venezuela, USA)	8

Due to the fact that the respondents of non-European countries are totally atypical respondents, they are not mentioned in the following results.

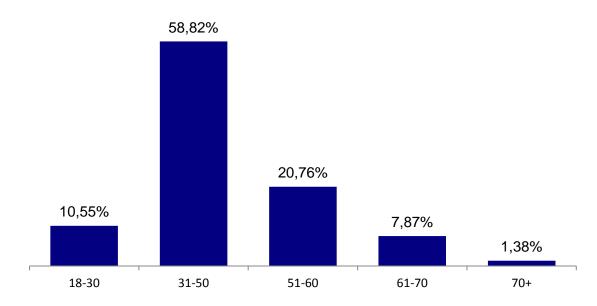
³ The patient representatives in the steering committee: Yoram Cohen (Israel), Flavio Prata (Italy), John Bowis (UK) and Raluca Nica (Romania)

I. Demographic characteristics of the respondents

Gender (Q2)

	All	EU 15	EU 12	Europe Non EU
	N=1156	N=421	N=413	N=314
Female	51,64%	48,22%	54,00%	49,20%
Male	48,36%	51,78%	46,00%	50,80%

Age of respondents (Q 5)



Specificity: Comparison with overall European population

	% respondents (n=1156)	% Overall EU (Eurostat)
18-30	10,55%	21,33%
31-50	58,82%	35,14%
51-60	20,76%	16,83%
61-70	7,87%	13,39%
70+	1,38%	13,31%

The respondents group is more than average an adult population, youngsters (<30) and older people (>60) are underrepresented

Civil status (Q6)

	All	EU 15	EU 12	Europe Non EU
	N=1156	N=421	N=413	N=314
Married / Further Marriage	24,05%	22,09%	24,94%	26,37%
Cohabiting Civil / Domestic partnership	5,88%	10,21%	3,87%	2,57%
Single / Unmarried	48,18%	49,41%	49,15%	45,34%
Divorced / Separated	17,99%	15,68%	18,64%	19,29%
Widow	2,42%	1,90%	2,66%	2,89%
Unknown	1,47%	0,71%	0,73%	3,54%

Highest education (Q7):

(red marked = more than 10% higher than overall, green marked = more than 10% lower than overall)

By country

	All	EU 15	EU 12	Europe Non EU
	N=1156	N=421	N=413	N=314
Primary education (> 12 yr)	14,62%	17,34%	9,69%	16,72%
Secondary education (> 18 yr)	49,13%	39,43%	52,06%	59,49%
University degree (bachelor)	14,71%	19,48%	11,86%	11,58%
University degree (master)	9,17%	12,83%	7,26%	6,75%
Other	12,37%	10,69%	19,13%	5,47%

Specificity: Comparison with overall European population

	% all respondents (N= 1156)	% EU respondents (N= 834)	% Overall EU (Eurostat)
Primary education	14,62 %	13,76%	30,79 %
Secondary education	49,13 %	45,80%	46,56 %
University degree (bachelor or master)	23,88 %	25,66%	22,65 %
Other	12,37 %	14,87%	0,00 %

Normal/usual housing situation(Q8)

	All	EU 15	EU 12	Europe Non EU
	N=1156	N=421	N=413	N=314
Own house/flat/apartment	46,97%	51,54%	45,28%	43,41%
Rented house/flat/apartment or room(s)	14,71%	22,09%	10,41%	9,97%
Non independent ^(*)	38,32%	26,37%	44,31%	46,62%

^(*)Non independent = Live with relative(s), Homeless shelter, Residential care home, Retirement community, Hospital, Supported housing, Other

Work situation (Q10)

	All	EU 15	EU 12	Europe Non EU
	N=1156	N=421	N=413	N=314
I work full-time	14,36%	13,54%	14,29%	15,11%
I work part-time	12,20%	13,30%	11,86%	10,93%
Unpaid work (volunteer / stagiaire)	4,67%	6,18%	3,63%	3,86%
Full-time student	2,25%	3,09%	2,66%	0,64%
I'm looking for a job	12,20%	12,35%	10,17%	14,47%
Retired	21,54%	16,39%	22,28%	28,30%
I receive benefits	14,62%	17,10%	12,59%	14,15%
I'm not able to work (disabled)	18,17%	18,05%	22,52%	12,54%

Living with (Q9)

	All	EU 15	EU 12	Europe Non EU
	N=1156	N=421	N=413	N=314
Married/Further Marriage	24,05%	22,09%	24,94%	26,37%
Cohabiting Civil/Domestic partnership	5,88%	10,21%	3,87%	2,57%
Single/Unmarried	48,18%	49,41%	49,15%	45,34%
Divorced/Separated	17,99%	15,68%	18,64%	19,29%
Widow	2,42%	1,90%	2,66%	2,89%
Unknown	1,47%	0,71%	0,73%	3,54%

Comments:

The respondent group is adult, higher educated, has contacts with patient groups, en is well recovered (cfr housing situation) \rightarrow this may give more positive results than for the all over population of people with mental health problems

II. Diagnosis of respondents (Q 13)

(red marked = more than 10% higher than overall, green marked = more than 10% lower than overall)

By country

	All	EU 15	EU 12	Europe Non EU
	N=1156	N=421	N=413	N=314
Schizophrenia	28,81%	20,90%	31,72%	35,69%
Bipolar Disorder	19,29%	39,67%	9,69%	3,86%
Depression	22,23%	15,20%	25,18%	27,97%
Other	18,17%	17,10%	19,61%	18,01%
Don't know/not sure	11,51%	7,13%	13,08%	14,47%

It seems that in Eastern Europe (the new EU countries) the diagnosis "Schizophrenia" is the most common diagnosis, and the diagnosis bipolar is not (yet) commonly introduced

III. Physical problems

Do you have physical health problem(s) (Q21)

(respondents could check more than one) (N=1156)

By country

Yes % of all respondents	All	EU 15	EU 12	EU 27	non EU
	N=1156	N=421	N=413	N= 834	N=314
Yes	85%	89%	83%	86%	85%

Comment:

A large majority of respondents are confronted with physical problems (All higher than 80%)

No difference between regions, no difference between diagnosises

By Diagnosis

Yes % of all respondents	All	Bipolar	Depression	Schizophrenia
	N=1156	N= 223	N= 257	N=333
	85%	89%	82%	86%

What kind of physical problems the respondents suffer from? (Q21)

(red marked = more than 10% higher than overall, green marked = more than 10% lower than overall)

By country

Yes % of all respondents	All	EU 15	EU 12	EU 27	non EU
	N=990	N= 374	N= 341	N= 715	N= 264
Weight	44,44%	54,81%	35,78%	45,73%	40,91%
Smoking	38,99%	40,11%	36,36%	38,32%	41,67%
Heart problems including blood pressure, cholesterol	25,96%	21,12%	29,62%	25,17%	26,14%
Eye problems	24,14%	14,97%	29,03%	21,68%	30,30%
Musculoskeletal problems (muscle/bone/joint)	16,57%	13,90%	13,49%	13,71%	24,62%
Problems with sexual life	14,85%	20,32%	10,85%	15,80%	12,12%
Other	14,04%	20,05%	14,37%	17,34%	5,68%
Problems in controlling body movements	12,53%	14,97%	11,73%	13,43%	10,23%
Diabetes	8,38%	8,82%	8,80%	8,81%	7,20%
Substance abuse/addiction	3,43%	2,67%	4,99%	3,78%	2,65%
Cancer	1,72%	1,87%	1,76%	1,82%	1,52%

By Diagnosis

Yes % of all respondents	All	EU 15	EU 12	EU 27	non EU
	N=990	N= 199	N= 212	N= 288	N= 291
Weight	44,44%	54,77%	35,38%	49,65%	38,83%
Smoking	38,99%	22,61%	33,02%	44,44%	49,83%
Heart problems including blood pressure, cholesterol	25,96%	11,56%	31,13%	21,88%	36,77%
Eye problems	24,14%	11,06%	25,94%	31,60%	29,90%
Musculoskeletal problems (muscle/bone/joint)	16,57%	9,05%	24,06%	13,54%	23,37%
Problems with sexual life	14,85%	12,56%	11,79%	14,24%	23,37%
Other	14,04%	11,56%	13,68%	10,76%	20,96%
Problems in controlling body movements	12,53%	6,03%	10,85%	13,54%	17,87%
Diabetes	8,38%	2,51%	6,60%	9,38%	13,06%
Substance abuse/addiction	3,43%	1,51%	4,25%	1,74%	5,15%
Cancer	1,72%	1,01%	3,30%	1,04%	2,41%

Was the physical illness diagnosed before or after the mental health problem? (Q23)

(% of respondents that have a physical problem)

By country

	all	EU 15	EU 12	EU 27	Non EU
	N= 1009	N= 381	N= 346	N=727	N=273
Before	36,27%	29,92%	37,57%	33,56%	43,59%
After	63.73%	70.08%	62.43%	66.44%	56.41%

By diagnosis

	all	Bipolar	Depression	Schizo	Other
	N= 1009	N= 202	N= 218	N= 291	N= 298
Before	36,27%	25,74%	46,79%	33,68%	38,26%
After	63,73%	74,26%	53,21%	66,32%	61,74%

Comments:

On average more than 60% of the physical problems were diagnosed after the mental health problems were diagnosed and could be considered as a side effect?

High figures for EU 15 and bipolar patients

IV. Experienced barriers to receive care for physical health problems (Q35)

Respondents could check more than one

(red marked = more than 10% higher than overall, green marked = more than 10% lower than overall)

Did not experience any barrier

% of all respondents	all	EU 15	EU 12	EU non EU
	N=1156	N=421	N=413	N=314
Experienced a barrier	41,70%	46,32%	33,17%	44,69%
No barrier	58,30%	53,68%	66,83%	55,31%

Did experience barriers:

By country

% of all respondents (N=1156)	all	EU 15	EU 12	EU non EU
	N=1156	N= 421	N= 413	N= 314
User charges (financial reasons)	15,40%	19,71%	11,38%	12,42%
Fear of disclosing my mental health problem(s)	7,27%	10,93%	3,39%	8,85%
Forgot appointment	7,27%	9,50%	5,33%	14,16%
Lack of referral	6,40%	8,55%	3,87%	8,85%
Appointment early in the day and did not get up	5,36%	6,18%	2,42%	11,95%

% of those who experienced barriers (N=482)	all	EU 15	EU 12	EU non EU
	N= 482	N= 195	N= 137	N= 142
User charges (financial reasons)	36,93%	42,56%	34,31%	27,46%
Fear of disclosing my mental health problem(s)	17,43%	20,35%	6,19%	8,85%
Forgot appointment	17,43%	17,70%	9,73%	14,16%
Lack of referral	15,35%	15,93%	7,08%	8,85%
Appointment early in the day and did not get up	12,86%	11,50%	4,42%	11,95%

By diagnosis

% of all respondents (N=1156)	all	Bipolar	Depression	Schizo	Other
	N= 1156	N= 223	N= 257	N= 333	N= 343
User charges (financial reasons)	15,40%	20,63%	18,68%	11,41%	13,41%
Fear of disclosing my mental health problem(s)	7,27%	8,52%	6,23%	4,80%	9,62%
Forgot appointment	7,35%	8,97%	6,61%	9,01%	5,25%
Lack of referral	6,57%	7,62%	5,06%	6,91%	6,71%
Appointment early in the day and did not get up	5,36%	7,17%	1,95%	7,51%	4,66%

% of those who experienced barriers (N=482)	all	Bipolar	Depression	Schizo	Other
	N= 482	N= 105	N= 104	N= 132	N=141
User charges (financial reasons)	36,93%	43,81%	46,15%	28,79%	32,62%
Fear of disclosing my mental health problem(s)	17,43%	18,10%	15,38%	12,12%	23,40%
Forgot appointment	17,43%	19,05%	16,35%	22,73%	12,77%
Lack of referral	15,35%	16,19%	12,50%	17,42%	16,31%
Appointment early in the day and did not get up	12,86%	15,24%	4,81%	18,94%	11,35%

Comments:

For 1 out of 6 respondents user charges are a barrier, for respondents with diagnosis bipolar up to 1 out of 5

V. Role of environment

someone close who encourages you to look after your physical health (Q30)

(respondents could check more than one)

(red marked = more than 10% higher than overall, green marked = more than 10% lower than overall)

By country

	all	EU 15	EU 12	EU 27	Non EU
	N=1156	N=421	N=413	N= 834	N=314
Parents	40,48%	24,23%	36,80%	30,46%	39,81%
Spouse	23,96%	24,23%	25,18%	24,70%	22,29%
Children	17,13%	33,97%	15,98%	25,06%	21,66%
Family	81.57%	82,42%	77,97%	80,22%	83,76%
Friends	29,93%	26,84%	33,90%	30,34%	28,03%
Colleagues	5,19%	4,28%	5,81%	5,04%	4,46%
Neighbours	3,89%	2,14%	2,42%	2,28%	7,96%
Not Family	39,01%	33,25%	42,13%	37,65%	40,45%
No-one	17,47%	14,73%	14,53%	14,63%	0,00%

By diagnosis

	all	Bipolar	Depression	Schizophrenia	Other
	N=1156	N= 223	N= 257	N=333	N= 343
Parents	40,48%	35,43%	26,85%	49,25%	45,48%
Spouse	23,96%	38,57%	32,30%	11,11%	20,70%
Children	17,13%	23,77%	26,85%	7,81%	14,58%
Family	81,57%	97,76%	85,99%	68,17%	80,76%
Friends	29,93%	25,56%	22,18%	36,34%	32,36%
Colleagues	5,19%	4,04%	7,00%	5,11%	4,66%
Neighbours	3,89%	2,69%	4,28%	4,80%	3,50%
Not family	39,01%	32,29%	33,46%	46,25%	40,52%
No-One	17,47%	18,83%	17,51%	15,92%	18,08%

Very important role of family (>80%). Less for colleagues and neighbours...

VI. Attitude

Do any of the following statements apply to you (Q28)?

N=1156	yes	no	Don't know
I watch my alcohol consumption	66,96%	19,29%	13,84%
I go to the GP (family doctor) for health checks	63,67%	30,80%	5,54%
I pay attention to my food intake:	62,63%	30,71%	6,66%
I go for regular checks with the dentist	51,04%	41,18%	7,79%
I do not smoke	47,92%	37,54%	14,53%
I regularly have my blood pressure checked	38,41%	52,94%	8,65%
I try to smoke less	36,51%	39,71%	23,79%
I get vaccinations when they are needed e.g. flu/meningitis/tetanus	36,33%	52,34%	11,33%
I take regular exercise	30,97%	59,08%	9,69%

Matter of concern (Q29).

		concerned			
	Very	concerned	Slightly	Not at all	n/a
Not being able to live life as you wish	30,36%	27,77%	15,83%	17,91%	8,13%
Weight gain/excess weight	19,29%	20,42%	18,86%	31,23%	10,21%
Dental health	16,70%	28,63%	21,45%	25,43%	7,79%
Personal hygiene	15,22%	27,85%	13,06%	35,81%	8,04%
Smoking	14,36%	16,52%	11,25%	44,12%	13,75%
Heart problems including blood pressure - cholesterol levels or heart abnormalities	11,42%	17,04%	17,30%	40,14%	14,10%
Other diseases or problems	10,47%	14,88%	14,97%	39,01%	20,67%
Problems with sexual life	10,29%	17,04%	16,18%	42,13%	14,36%
Problems in controlling movement of the body (trembling or shaking)	9,00%	14,19%	19,90%	42,65%	14,27%
Diabetes or blood sugar abnormalities	6,14%	8,04%	10,81%	56,06%	18,94%
Use of illicit/illegal drugs	5,28%	3,20%	2,68%	63,84%	25,00%
Alcohol intake	5,62%	7,27%	17,73%	50,69%	18,69%

Last health checks (Q32)

N=1156	Last 3	Last 6	Last 12	>Year	Never
2					
Physical examination	29,15%	13,49%	16,35%	27,51%	13,49%
Weight	51,04%	13,24%	9,08%	13,84%	12,80%
Blood pressure	50,00%	14,53%	11,51%	12,46%	11,51%
Blood tests	46,80%	18,34%	15,74%	12,89%	6,23%
Dental checks	29,07%	16,87%	20,07%	25,17%	8,82%
Body Mass Index (BMI)	17,30%	6,06%	8,22%	18,86%	49,57%
Eye tests	15,92%	10,81%	18,69%	39,01%	15,57%
Waist measurement	15,31%	7,35%	9,60%	22,32%	45,42%
Problems in controlling movement of the body (trembling or shaking)	14,27%	4,67%	6,57%	15,57%	58,91%
Hearing tests e.g. for tinnitus	6,40%	3,37%	7,01%	35,29%	47,92%

VII. Information

At the moment of the prescription, did the mental health care professional ask about the medications that may have been prescribed for any <u>physical</u> condition (Q19)

(red marked = more than 10% higher than overall, green marked = more than 10% lower than overall)

	All	EU 15	EU 12	EU 27	Europe non EU
	N=1156	N=421	N=413	N= 834	N=314
Yes	46,63%	44,42%	44,79%	44,60%	51,13%
No	38,84%	39,43%	43,58%	41,49%	32,15%
Don't Remember	14,53%	16,15%	11,62%	13,91%	16,72%

By diagnosis

	All	Bipolar	Depression	Schizophrenia
	N=1156	N= 223	N= 257	N=333
Yes	46,63%	48,43%	54,86%	42,94%
No	38,84%	34,08%	31,52%	43,24%
Don't remember	14,53%	17,49%	13,62%	13,81%

Information: By Physical Health care professional (Q24)

(At the moment of the prescription, did the healthcare professional ask you about the treatment that may have been prescribed to you for any mental health problem(s)?)

By country

	All	EU 15	EU 12	EU 27	Europe non EU
	N=1156	N=421	N=413	N= 834	N=314
Yes	42,13%	38,72%	41,65%	40,17%	46,95%

By diagnosis

	All	Bipolar	Depression	Schizophrenia
	N=1156	N= 223	N= 257	N=333
Yes	42.13%	44.39%	48.25%	40.24%

Information (in both directions: the mental health prof about physical problems and the physical health professional about mental health problems) is low (<50%)

Information by Psychiatrist (Q26).

(Did your psychiatrist ever explain how mental illness could affect physical health?)

By country

	All	EU 15	EU 12	EU 27	Europe non EU
	N=1156	N=421	N=413	N= 834	N=314
Way Too much	2,85%	4,51%	0,24%	2,40%	2,89%
Too much	5,54%	3,56%	11,62%	7,55%	3,22%
About Right	50,00%	70,07%	42,86%	56,59%	50,16%
Way Too little	21,97%	20,43%	40,44%	30,34%	25,08%
Too little	19,64%	1,43%	4,84%	3,12%	18,65%

By diagnosis

	All	Bipolar	Depression	Schizophrenia
	N=1156	N= 223	N= 257	N=333
Way Too much	2,85%	3,14%	3,89%	3,60%
Too much	5,54%	5,38%	7,78%	5,41%
About Right	50,00%	50,22%	49,42%	50,15%
Way Too little	21,97%	23,32%	20,23%	19,82%
Too little	19,64%	17,94%	18,68%	21,02%

Comment:

Half of the respondents are not satisfied with the explanations of the psychaitrist

VIII. Appreciation

Appreciation of care for physical health by psychiatrist (Q25)

By country

	All	EU 15	EU 12	EU 27	Europe non EU
	N=1156	N=421	N=413	N= 834	N=314
Way Too much	4,76%	3,09%	5,57%	4,32%	6,11%
Too much	7,18%	8,79%	8,23%	8,51%	5,14%
About Right	61,76%	63,42%	59,56%	61,51%	63,02%
Way Too little	15,66%	14,73%	15,25%	14,99%	16,40%
Too little	10,64%	9,98%	11,38%	10,67%	9,32%

By diagnosis

	All	Bipolar	Depression	Schizophrenia
	N=1156	N= 223	N= 257	N=333
Way Too much	4,76%	3,14%	6,61%	8,11%
Too much	7,18%	9,42%	7,00%	6,01%
About Right	61,76%	62,33%	63,04%	57,96%
Way Too little	15,66%	16,14%	14,40%	15,62%
Too little	10,64%	8,97%	8,95%	12,31%

Overall appreciation of health care.(Q36)

By country

	All	EU 15	EU 12	EU 27	Europe non EU
	N=1156	N=421	N=413	N= 834	N=314
Way Too much	5,54%	3,80%	7,26%	5,52%	5,79%
Too much	10,55%	9,50%	12,83%	11,15%	9,00%
About Right	60,64%	62,95%	57,38%	60,19%	62,38%
Way Too little	17,21%	17,34%	17,19%	17,27%	16,08%
Too little	6,06%	6,41%	5,33%	5,88%	6,75%

By diagnosis

	All	Bipolar	Depression	Schizophrenia
	N=1156	N= 223	N= 257	N=333
Way Too much	5,54%	2,69%	6,61%	7,51%
Too much	10,55%	13,45%	10,89%	10,81%
About Right	60,64%	56,50%	61,87%	59,16%
Way Too little	17,21%	22,42%	15,56%	15,62%
Too little	6,06%	4,93%	5,06%	6,91%

IX. CONCLUSIONS

At the Regional Seminar June 2012 in Larnaka (Cyprus) participants from 14 countries discussed the first draft of this report.

Their conclusions were:

- Better communication between GP and Psychiatrists is needed and should be promoted > suggestion: introduction of a case manager to centralise all information regarding the treatment path of the patient (physical, mental, social).
- **Better training of professionals** to increase awareness of the link between physical and mental health issues (For example: training of GP and Psychiatrists).
- Patients need clear and honest information on the physical side effects of the medication they need to take for their mental health problem (weight gain - diabetes, cholesterol – increased smoking, tremors, and sexual problems).
- Professionals should pay **enough attention to the physical side effects** and should do everything possible to reduce them as this will contribute to the quality of life of the patients.
- Remove the barriers to get help for physical problems:
 - o financial reasons (consultation fee of GP)
 - o stigma (patients do not want the GP to know about their psychiatric problems)
- Patients have to take good care of themselves: take responsibility and assume their part in the treatment, within the therapeutic alliance between patients and professionals.

What needs to be done?

In line with the recommendations of the Mental and Physical Health Charter, GAMIAN-Europe would like to underline the importance of

- recognition of the links between mental and physical health;
- addressing these in all EU and national level health-related initiatives strategies and programmes;
- integrated mental and physical health care as a rule rather than an exception;
- ensuring adequate structures and processes in health systems (e.g. training and guidance to health care for all stakeholders involved:
- appropriate monitoring structures, benchmarks and performance assessments to ensure the implementation of policies supporting integrated care;
- improved communication and cooperation between all stakeholders involved;
- good practices exchange and implementation as well as guidelines for improved recognition, monitoring, diagnosis and management of combined mental and physical health problems;
- adequate resources and training for primary care providers;
- combating stigma and discrimination associated to mental and physical health problems;
- investment in research and learning about the reasons, consequences and costs of combined mental and physical health challenges, and how to deal with them.

X. Annex

On 2 June 2012, four patients with mental and physical health problems were interviewed Cyprus, to explore the connection between their mental and physical health, the challenges they have encountered in receiving the appropriate treatment, their experience with the professional care system, and their perspective on how public health systems should better address the link between mental and physical health.

Interview: Pedro

Age diagnosed with illness: 21

Type of illness: Cardiac disease

Do you see a link between your mental and physical health?

I was a sportsman and now play rugby. I was diagnosed when I had a heart attack after I played 4 football matches in a row.

I have a brain illness and my brain asks my body to do too much. Some medication I take is not good for my body.

My physical health has had an impact on my mental, as I suffer from obsession.

I have been taking the medicine since the age of 21.

Before the age of 41 I did not have any physical health checks.

Support system: I have a very supportive wife and 2 children in Portugal.

Challenges:

Doctors do not communicate to each other. I never brought a report from one doctor to the other.

For many years I could not have a family doctor because the state could not provide one for me. There was a shortage of family doctors and the health system and poverty in the country prevented centralized care. **Referral to family doctors was private, not through a family doctor**.

State of physical health:

I quit smoking last year, which should help me lose weight. I used to smoke 2 packs a day.

I go to the doctor more regularly for check-ups now and am starting to do other check-ups like prostrate.

Side effects of treatment: I had weight gain after treatment

How healthcare can be improved:

I think there should be a process so the patient can choose the way he's treated. The money goes to the patient to choose the association to provide the better service.

The focus should be on the treatment

Interview: Rebecca

Age of diagnosis: 28

Type of illness: Bipolar disorder

Do you see a link between your mental and physical health?

Yes, weight gain. My personality tends to be an emotional eater which may be linked to the

mood

Side effects from treatment:

I suffered weight problem and gained 10 kilos after I began medication. It was a **side effect of the medication**. I realized myself by reading and talking to other patients. First few years

spent my life getting stable and getting my life back together and the weight problem.

Physiatrists should be addressing the side effects and help with it from day one. I hear many people with bi-polar complain about weight problems and that's one of the reasons they don't adhere to treatment. **Psychiatrists should provide some support**. When people wait a year, they may gain more weight and become unhappy before they can actually do something. **The earlier the service can be offered, the better**. Don't wait a year by the time you gain 10

kilos and are unhappy, stop medication and then you relapse.

Diagnosis:

Bipolar disorder. I was diagnosed in 2001. It **took 2 years for the right diagnosis**. The doctors gave anti-psychotic and I gained weight. In 2004 I went to dietician, still taking medication but had the correct diagnosis: bipolar disorder (lytceum). I also had a tendency of gaining weight. It didn't stay stable because I didn't continue with the diet and lifestyle

changes.

The family doctor followed the Lyceum levels at the request of the psychiatrist. He had to focus on my blood levels and sometimes asked about it. As the years progressed and I was

stable, then it was fine.

I have a **new GP** and **he just listens**. My **GP** did not suggest psychical health check, but I did myself this year. **In Belgium, patients have a lot of freedom but maybe that's not good**. The upside is that you can change your psychiatrist or medical professional if you are

not progressing with your new doctor.

Treatment:

Last year went to the dietician again and lost 8 kilos. My psychiatrist understood that being overweight was a risk so we addressed it. I told her I was unhappy about my weight, my boyfriend was putting pressure and my psychiatrist agreed.

Support system:

I tried a lot of things that were expensive but I couldn't do it on my own. I needed external help and a structure. If the psychiatrist could get a dietician or family doctor on board, that would

help.

I had some patients in groups that had gastric bypass. We had a dietician come to speak to the group and that was really helpful. We didn't talk much about the issue in the group but once we did it was much appreciated. We usually talk about the situation based on the illness.

Self-help groups support you by introducing you to people with the same experience who can give you advice for your overall well-being and information. It is a source of information exchange.

How healthcare can be improved:

Money should go to the patients rather than the service providers.

The patients should be allowed to choose.

Investing in food and diet programs at low cost would be good as well as working in teams and providing support to get help. It would be good to have something cheap and effective to be offered with medication. It's also your own effort and own will to be simulated.

There's a trend in our groups in Belgium that patients say they were recommended by psychiatrist or psychotherapist. The latter years there has been more acceptance and referrals from the professionals. It could be better.

As Pedro said, be the master of your own treatment. But it can be really hard when you're sick to make those decisions. That's something the system in Belgium should check so patients don't get stuck.

If there's a central person to coordinate treatment, then care would be improved. Someone could activate a different view in treatment of both physical and mental health.

There are two worlds and they don't meet. There should be more cross-training of these doctors.

Interview: Patrick

Association: French Depression Association

Type of illness:

Bipolar disorder

Alcohol problem that contributed to weight gain

Diagnosis:

I wasn't suffering but I had gained weight. I asked about the weight gain but the doctors said I had to eat less and exercise but they didn't tell me it was due to medication.

Later I was hospitalized for a manic state of bi-polar. I had pains in my kidney and they gave me a painkiller but didn't take it seriously. I asked for a physical health doctor to come and he did some checks and said I was ok. I had very bad pains the whole time. I complained all night about the pain and they finally brought me to the physical health side of the hospital where I was rushed to surgery and re-animated.

I had a history of kidney problems and the psychiatrist should have known that lytceum was high risk for kidney disease.

Treatment:

I followed the advice of the doctor without questioning. Psychiatrists were imposed because I was in hospital.

Three years ago I was on many medications but now I only take one kind of medication. When I have a problem, I force myself to stop. I go to sleep. After when I am rested, I feel better.

Support system:

I took **Asian relaxing techniques** (yoga, karate, etc). I found a leaflet on tai chi and went to the class to see what it was. At the beginning, I didn't have any balance so it was hard to do but then I was able to do it. **It helps me and is like a new medication**. I created a small program for 30-45 minutes every morning. The program **enables me to reduce my anxiety and sleeping medication**. I only have mood stabilizers now.

Do you see a link between your mental and physical health?

My physical health was neglected because I was a psychiatric patient and admitted for mental health problems. Doctors prescribed medication and then don't look to make the best of the medication and adjust treatment as needed.

It's also **necessary to have the same doctor**. If you change too much, it's difficult for the patient to follow the treatment. Make sure your psychiatrist is good and listens. Confidence in your doctor is very important. Trust and empathy is very important.

In France, some doctors now are technical. GPs have 20 minutes per patient and get paid per consultation. There is **no time to discuss your treatment**. Doctors have no empathy they just give medication and technical advice. **In France, the doctors need to have more time and more information.**

Side effects from treatment:

Another bad side is when you read the medications you see all the side effects. There's no one to inform patients which one affects them. There should be better explanations for the patients so they can make the best decision and know they won't have all these side effects. Right now there's a lot of fear when you read the legalistic medications.

Everyone should get the tools and support going next to the medication. It's very important to get a structure in your life, sleep, watch stress, eat healthy, and don't drink too much. A healthy lifestyle is very important.

How healthcare can be improved:

I think it's necessary that there is **communication between the doctor and patients**. When a doctor tells a patient they must take medication (anti-psychotic), with neuroleptic, they often don't understand why. Neuroleptic causes a change but you don't really feel anything so you think, why should I take it? The effect is different for every person and patients don't understand that.

There should be a **protocol agreement for relations between patients and doctors**. Doctors should explain more, why certain medication is necessary even if you don't see the immediate effect.

In mental health you cannot see what's wrong. **Information is the most important.** The main reason I created an association in my town is to give information and to get information for myself. It's possible for you to find a solution and to correct the situation. You are better prepared to face the illness and the consequences with the information.