

Report on Kingston Community Services Survey (February to June 2022)

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1. Purpose of The Survey

Kingston Mental Health Carers' Forum (KMHCF) is a small charity in RBK representing Mental Health Carers in the Borough.

For some years, at the monthly carer support group meetings we have heard stories about the difficulties carers face and sometimes how difficult it has been to get support from community services. Also there have been reports of shortcomings in local services affecting service users and carers. This survey is to discover something about the current state of these services from the carers' perspective, to collect details of the carers' experiences and to record their opinions.

The survey was available online and consisted of 22 questions, 5 of which allowed longer textual replies. The other questions were mostly multiple choice which established the participant's role, status, relationship to secondary services and level of satisfaction. It is acknowledged that those with negative experiences are more likely to participate in a survey of this kind.

KMHCF has around 120 members. Approximately 1 in 6 of those responded to our survey.

2. Scope

2.1. Publicity

The survey was advertised to all KMHCF members and with other relevant local organisations and publications including:

Kingston Carers' Network
YMCA Surbiton
Chessington Chat
Berrylands Companion
Malden's Village Voice
Surrey Comet
SWLStG Carers Quarterly Newsletter
Mind in Kingston
Fircroft Trust
Healthwatch Kingston
plus 2 Facebook groups

It is not possible to know the precise number of recipients, but it is likely to be 200+

2.2. Response and Categorisation

21 responses were received over the period. From the answers to questions 1 to 4: 19 were unpaid carers and therefore relevant to this survey. All cared for family members. Of these 12 received support from Secondary Community MH services in Kingston and 7 did not. Out of these 4 wanted to receive support for their person. Of the three who did not want to receive support, two had been assessed and rejected for support.

3. Comments about the Community Services

All of the responses to the survey are contained in appendix B

3.1. Positive

B.6b.6 - "on the whole I am satisfied with the care my son receives especially as he is in a Hestia house and has help there."

B.6b.6 - "References from my sons care worker to the home treatment team have been wonderfully useful and I feel they are an essential part of the set up."

B.6b.6 - "Care has been difficult these last years but, I do feel people try to help"

B.6b.7 - "My family member a good Care Coordinator who has been in place for many years, and maintains regular face-to-face contact."

B.6b.8 - "Difficult in beginning of illness but, since stabilised, experienced good support."

B.14.7 - "There has been no difficulty with the level of support"

3.2. Negative

Some common themes:

- There is often little or no contact from Community Services with MH Carers.
- Inability to contact Community Services, as Carers do not have contact details of the relevant Support Worker.

- Annual Reviews for both Service User and their Carer with both Psychiatrist and Support Worker in attendance either infrequent or non-existent.
- The much-vaunted Triangle of Care not evident in services.
- MH Carers not offered regular assessment of needs.

4. Criticisms and Shortcomings of the Community Services

We have categorised types of criticisms under the following titles. Some responses are duplicated as they fit more than one categorisation.

4.1. Serious Errors Made

B.6b.1, B.18.1 (refer to appendix B for the full text)

These comments report negligence, breaches of MH legislation, the equality act and health and social care act. Also, the quality of care is criticised and the honesty of trust workers resulting in trauma to the patient and the family. These are obviously very serious claims made by one respondent and it would be interesting to know how any complaints to the trust were investigated. Perhaps the person who made the comments would like to relinquish their confidentiality in order for further details to be known including the mentioned CQC findings.

4.2. Lack of care for patients

There were 12 different comments about care for patients were given.

B.5.3 - Thinks there should be a "day centre with different therapies"

B.6b.1 - "The 'care' provided is woefully inadequate and has resulted in avoidable hospitalisation and trauma."

B.6b.5 - "neither of us have heard from support services in recent times."

B.6b.6 - "The care worker is tricky to get hold of and at times the dr is not available as often as needed."

B.6b.9 - "Support has been patchy and I think that resources are limited."

B.6b.10 - "Sadly there has been a lack of continuing care."

B.14.1 - "Proper treatment based on the individual patients actual needs should be put in place."

B.14.6 - "More regular apptmt with the consultant"

B.18.1 - "Appropriate treatment, such as therapy and OT is either denied or has very

long waiting lists."

B.18.8 - "Had limited support from ICOPE services" (Not SWLStG responsibility)

B.19.2 - "the individual with mental health problems in the community does not receive enough attention."

4.3. Lack of Contact or Poor Contact with services

There were 11 different comments about this.

B.5.2 - "All he has is medication every three months & a yearly invite."

B.6b.5 - "I don't know if my son has a support worker"

B.6b.6 - "The care worker is tricky to get hold of and at times the dr is not available as often as needed."

B.6b.10 - "It is impossible to get in touch with allocated professionals by telephone when needed."

B.6b.11 - "Chasing appointments, trying to speak to Consultants and getting right support for the person I'm caring for can be time consuming and take over completely."

B9 - 3 said that no one was in touch

B10 - 8 said that they do not have the contact details of the staff member of the MH team who has prime responsibility for the person they care for. (eg Consultant Psychiatrist)

B11 - 8 said that they do not have the contact details of the staff member of the MH team who has routine responsibility for the person they care for. (eg Care Coordinator/ Key Worker)

B12 - 8 said that they were not invited to a review (at least annually) with a Consultant Psychiatrist and support team.

B13 - 3 said that they had received below average levels of support consistency over time, particularly during this period of the pandemic?

B.14.5 - stated "It is surely a basic requirement of M.H care for both the carer, and the person he cares for to have regular contact with support services, and to have the contact details of the support worker and or team." implying that this was not being received.

B.18.6 - "At one time i was always invited to my son's annual review with hi psychiatrist. That hasn't been the case for some years now."

4.4. Lack of support for carers

This was referred to in 6 responses.

B.5.1.3 - mentions lack of "A stand-in carer from time to time."

B.5.2 - "I don't know what my Son receives."

B.6b.4 - Two people said that the Triangle of Care is not working.

B.6b.4 - "There is very little, if any, support for the person's Carer."

B.6b.5 - "I as his carer have had no contact with support services for almost 5 years."

B.5.1 - A carer explained at length the difficulty of caring for a family member who does not engage and the little support they have received.

B.18.4 - "Contacting the Carer giving them updates of progress etc would help as my Son receives letters & doesn't ever read them so he gives them to me."

B.18.5 - "More help and support is needed for Carers who are on duty 24/7, and have to deal with and make decisions on challenging behaviour daily. Caring is a very lonely role."

4.5. Vagueness and unclear communication

B.5.2 - "I don't know what my Son receives."

B.6b.9 - "Often mixed messages get given to us all."

B.6b.11 - "Chasing appointments, trying to speak to Consultants and getting right support for the person I'm caring for can be time consuming and take over completely."

B.14.1 - Complains of lack of "Honesty and proper communication from trust. Faster response to concerns raised."

B.14.9 - "More knowledge about activities and support in the local community that are for everyone. Better communication."

B.18.4 - "Contacting the Carer giving them updates of progress etc would help as my Son receives letters & doesn't ever read them so he gives them to me."

4.6. Not listening to Carers

B.14.1 - "Carers to actually be valued rather than tick box policies that aren't followed through."

B.14.11 - "Remind the support staff that Carers at time are drained and exhausted."

B.18.4 - "Contacting the Carer giving them updates of progress etc would help as my

Son receives letters & doesn't ever read them so he gives them to me."

B18.12 - "The mental health professional should seek the carer's input when making an assessment of their client's current mental health condition." "The last report on my husband was inaccurate."

B18.13 - "Don't assume if patient lives with family that they don't need on going help. Listen to the carers if they raise concerns, especially if they oppose discharge from a service ie Home Treatment Team. Prevention of hospital admissions could have been avoided."

B.19.9 - Asks for "Any help to deal with mental health and to be listened to."

4.7. Inadequate Care

B.6b.1 - "The care provided has been negligent at best and dangerous" plus 5 other damning criticisms.

B.14.2 - "He should be seen at least annually for a review to ensure things are not getting worse."

B.14.4 - Complains of lack of "Regular reviews."

B14.5 - "It is surely a basic requirement of M.H care for both the carer, and the person he cares for to have regular contact with support services, and to have the contact details of the support worker and or team."

4.8. Inconsistent Care

B.14.8 - Asks for "More consistent care between the teams"

B.18.7 - for "The care worker to see the clients on a regular basis"

4.9. Lack of Crisis support

Two respondents reported problems getting help in a crisis.

B.5.6 - "When in a crisis support is very hard to find".

B.19.9 - ".. told no help you can go to the other side of London that's not good enough when it's needed .."

4.10. Lack of Support for People who are difficult to engage.

B.5.1 - "More effort should have been put into engaging with my cared for person to win their trust."

B.5.7 - "lack of support for carers who care for people who do not want to engage"

B.5.1 - "More effort should have been put into engaging with my cared for person to win their trust." and speaks at length of a seemingly impossible situation that has gone on for 11 years.

B.19.10 - "No - the individuals we have encountered in the past have all been professional but the parameters of what can be offered (i.e. to people who don't engage) are limited."

KMHCF comment: This issue raises the question whether people who do not engage should be provided with services. The argument has been made that it is difficult to provide services for someone who does not engage. This may be true but it is another step to say that it is impossible. This is also potentially a changeable situation as someone not currently engaging might engage in the future. As we have seen acceptable services are supplied to autistic people who are known for not engaging. The main issue is that these situations are not uncommon and cause immense difficulties for carers putting them under considerable pressure and potentially damaging their mental health. The question is can the service providers continue to say that "nothing can be done in these situations".

4.11. Lack of Follow up

Two respondents mentioned lack of follow up after hospitalization:

B.6b.2 - "There is no regular follow-up to monitor the mental state of the person I care for, so that he could get into serious difficulties if he was not being observed by his family"

B.6b.3 - "There is no follow up once the patient is discharged from the hospital. Mental illness is not an illness which can be treated with just medicine only. It requires not only follow up but must also include rehabilitation"

B.18.1 - "Appropriate treatment, such as therapy and OT is either denied or has very long waiting lists."

4.12. Difficulties in making contact with services

B.5.1 - "There follows countless excuses & delays whenever I have initiated contact, always leading to no avail & causing a great amount of stress to myself as a carer."

B.6b.5 - "That is his only contact with support services. I as his carer have had no

contact with support services for almost 5 years."

B.9 - 3 said that no one was in touch

B.14.5 - "It is surely a basic requirement of M.H care for both the carer, and the person he cares for to have regular contact with support services, and to have the contact details of the support worker and or team."

B.18.4 - "Contacting the Carer giving them updates of progress etc would help as my Son receives letters & doesn't ever read them so he gives them to me."

B.18.9 - "The Trust needs to keep clients and Carers up-to-date with contact details of the current Consultant."

B.18.10 - "No one to help or talk too always get passed to someone else and then dropped like a bag of coal."

4.13. The Services passing responsibility around

B.5.6 - "When in a crisis support is very hard to find. I get passed from pillar and post no one wants to take responsibility often or not I'm left to deal with his mental health own my own."

B.5.1 - "There follows countless excuses & delays whenever I have initiated contact, always leading to no avail & causing a great amount of stress to myself as a carer."

B.6b.2 - "He is then immediately discharged back to the GP and it is left to the family to see if his medication seems to keep him stable, which is obviously an unsafe situation."

B.18.10 - "No one to help or talk too always get passed to someone else and then dropped like a bag of coal."

4.14. Unfavourable Comparison with past services

B.18.2 - "In 2018, the previous time of asking for help, a young student nurse (CPN) came out, along with the assessor, on the home visit assessment; how very refreshing she was! she listened, showed compassion & really wanted to help"

B.18.2 - "The care was intended, by the year 2000, to be delivered within the community, but the reality is so often that there is no care! "

B.18.6 - "Over the time i have been a Carer (20 years +) the standard of secondary care seems to have dramatically deteriorated from what i experienced some years ago."

4.15. Only receiving help when in a crisis

B.6b.10 - "It is extremely difficult to get back into Secondary Care once discharged. Only a serious crisis will enable this."

B.18.2 - "Why do the mental health teams always wait for crisis? Why not be proactive & pre-empt crisis altogether?"

4.16. The Slowness and Inefficiency of the referral system

B.6b.2 - "it is always necessary to request a referral by the GP before he even gets a telephone consultation from a psychiatrist. He is then immediately discharged back to the GP and it is left to the family to see if his medication seems to keep him stable, which is obviously an unsafe situation."

B.6b.4 "My husband has been "referred back to GP" many times whilst still needing the support of a Mental Health Team. It is extremely difficult to get referred back into Secondary care." and two went on to say 'I would add that "referred back to GP" is an euphemism for "referred back to Carer!"'

B.6b.10 - "It is extremely difficult to get back into Secondary Care once discharged."

4.17. Lack of adequate Care Plans

B.7 - Five respondents replied no to this

B.8 - Three respondents replied with a less than adequate care plan.

B.18.1 - "Professionals tend not to read patient notes prior to review meetings, care plans are not reactive and appropriate as a result."

4.18. Triangle of Care not adhered to

B.6b.4 - "The so-called Triangle of Care doesn't seem to be working in practice."

B.6b.10 - "Whatever happened to the Triangle of Care?"

B.18.12 - "Whatever happened to the Triangle of Care!?"

4.19. GP support Inadequate (*We realise that this is not SWLStG responsibility*)

Whereas the GP service is defined as primary care this is the means by which Secondary Care is accessed and it is vital that shortcomings should be addressed.

B.19.4 - "GPs are not sufficiently trained to diagnose and treat mental health problems. There should be a mental health professional at every GP surgery to

oversee and navigate a patient through the whole process of getting mental health support. GP surgeries need to be provided with this information."

4.20. Infrequent Carers assessment

(We realise that this is not SWLStG responsibility)

B.16 - 1 respondent gave the date of the last carers assessment more than 5 years ago, one more than 10 years ago.

B17 - 2 respondents replied that their needs have significantly increased since their last Carers' Assessment.

B.18.11 - "Although I did receive a Carer's Assessment six years ago, I have not had one recently."

4.21. Services Affected by Cutbacks

B.18.3 - "The social groups for people with autism etc have been cut back far too much."

B.19.3 - "It seems the mental health department is hit by funds and shortage of staff and in such circumstances the result will be not very good for the patient and more so for the Carer."

B.19.8 - "Kingston Carers' Network has been excellent but sadly has had some of its finance taken away by Kingston, including the costs of the lady who ran the dementia group."

B.6b.9 - "Support has been patchy and I think that resources are limited."

4.22. Other miscellaneous criticisms

B.18.2 - "In 2022, with the long standing slogan of 'time to change, time to talk', KMHT should have by now moved on with the times & on from the old style MH practices of 100 years ago! It is apparent that still the 'so-called services' predominant answer is to section or do nothing.

There is the latest talk of open dialogue' (from Finland) but like everything else it would appear to be all talk so far & no action; yet this innovative & promising method could have so much more potential. There is a saying 'a stitch in time saves nine' - if prevention was the priority rather than waiting for for a crisis to happen it would save not only so much money, but people's lives, which is paramount. Why do the mental health teams always wait for crisis? Why not be pro-active& pre-empt

crisis altogether?

The last occasion I asked for help was in early October 2021 & despite one safeguarding SW visit in late October, no one came back, despite chasing on numerous occasions for a social worker to come out on a further visit (as promised by the initial 2x SWs, following allocation of a further SW). Finally towards the end of January 2022 someone was talking of arranging a visit, but by then it was far too late, 3 1/2 months too late. To explain, in late October the first two SWs promised to come back to visit, so this was incredibly damaging making a promise & breaking it, especially as my cared for person originally shut themselves off due to severe trust issues & through bullying. Trust & continuity should have been key here. I am now dealing with the situation myself as I am not prepared to take the detrimental effects of fighting for help any longer (over 11 years) as I absolutely have to protect my own mental & physical health in order to remain strong in my caring role."

5. Suggestions given by respondents for improvements to the Service

B.5.1 - "Listen to the carer, take action in a more pro-active manner, try talking more, both to the carer & the person with mental health problems, in order to win their trust & treat them with respect & dignity. Take some time & then reap the results of taking that time. "

B.5.3 - "day centre with different therapies such as mindfulness, small discussion groups, activities, art, complimentary therapies, individual/group counselling, well - being/health/education sessions"

B.5.4 - "A stand-in carer from time to time."

B.18.4 - "Contacting the Carer giving them updates of progress etc would help as my Son receives letters & doesn't ever read them so he gives them to me."

B.18.5 - "More help and support is needed for Carers who are on duty 24/7, and have to deal with and make decisions on challenging behaviour daily. Caring is a very lonely role."

B.18.7 - "The care worker to see the clients on a regular basis.. If they are doing well every 2-3months...but to see them to keep up with how they are doing."

B.18.9 - "Over the years, there have been changes in Consultant Psychiatrists. The Trust needs to keep clients and Carers up-to-date with contact details of the current

Consultant."

B.18.12 - "The mental health professional should seek the carer's input when making an assessment of their client's current mental health condition. When in a bi-polar manic period, the client is in an "alternative reality" and his or her perception of their current mental health condition cannot therefore be trusted. A carer is with their client 24/7 and I would have imagined a psychiatrist would have considered his or her input ESSENTIAL"

B.18.13 - "Don't assume if patient lives with family that they don't need on going help. Listen to the carers if they raise concerns, especially if they oppose discharge from a service ie Home Treatment Team. Prevention of hospital admissions could have been avoided."

6. Conclusions

We consider the following items to be essential to M.H Carers:

- 6.1.** The name and contact details of the Support Worker responsible for the one they care for.
- 6.2.** Regular contact from Support Worker with both the Carer and Service User, and changes in both personnel and their contact details sent to both of the above.
- 6.3.** An Annual Review with both the Psychiatrist and S.W in attendance offered to both Carer and Service User.
- 6.4.** An offer of an assessment of needs offered annually to Carers.
- 6.5.** All of the above to be an integral part of the Community M.H Transformation project for Kingston which is currently in progress.
- 6.6.** We appreciate the current economic situation, staff shortages and not least the Covid pandemic has had an impact on services in recent times but believe they can and should improve.

Appendices

A - The questions

B - The responses

C - Terminology

APPENDIX A - The questions

These are numbered according to question number prefixed by "A.".

Category of respondents

This comes from the answers to questions 1 to 4

A.1 Are you an unpaid Carer/Family/Friend for someone in Kingston who experiences

Mental Health difficulties? *

Carer/Family -> Go to

Q2 Friend -> Go to Q2

No This ends the survey

A.2 Does the person you care for receive support from Secondary Community MH

services in Kingston (ie from SW London & St George's MH Trust)? *

Yes -> Go to Q6

No -> Go to Q3

A.3 Does the person want to receive support?

Yes

No

A.4 Has the person been assessed and rejected for support?

Yes

No

A.5 What, in your opinion, should they receive and why don't they?

A.6a What is your experience of this care?

The following options were given:

Not specified

Fair

Good

Inadequate

Poor

A.6b Could you say more about your experience:

A.7 Does the person you care for have a current Care Plan?

A.8 Do you consider this Care Plan to be adequate?

A.9 Is any member of the MH Support Team at Tolworth Hospital in regular contact with you and/or the person you care for?

A.10 Do you have the contact details of the staff member of the MH team who has prime responsibility for the person you care for? (eg Consultant Psychiatrist)

A.11 Do you have the contact details of the staff member of the MH team who has routine responsibility for the person you care for? (eg Care Coordinator/ Key Worker)

A.12 Are the person you care for and you invited to a review (at least annually) with a Consultant Psychiatrist and support team.

A.13 Has the level of support received been consistent over time, particularly during this period of the pandemic? (1 to 5, 5 being best)

A.14 How would you expect the level of support (with or without the pandemic) to be improved?

A.15 Have your own Carer needs been assessed at any time?

A.16 When was your last Carers' Assessment?

A.17 Do you feel that your own needs have significantly increased since your last Carers' Assessment?

A.18 Are there any other relevant details around the MH Support Team services you would like to bring to our attention?

A.19 Although this survey is specifically concerned with the Secondary Community MH services in Kingston provided by SW London & St George's MH Trust, do you want to make any comments about other services?

A.20 How did you hear about this survey.

A.21 If you would like to enter the Prize Draw, please give your name and email address

APPENDIX B - Responses to the questions

These are numbered according to question number prefixed by "B." .

B.1 Are you an unpaid Carer/Family/Friend for someone in Kingston who experiences Mental Health difficulties?

Carer/Family 19

Friend 0

No

B.2 Does the person you care for receive support from Secondary Community MH services in Kingston (ie from SW London & St George's MH Trust)?

Yes 12

No 7

No Reply 2

B.3 Does the person want to receive support?

Yes 4

No 3

No Reply 14

B.4 Has the person been assessed and rejected for support?

Yes 2

No 5

No Reply 14

B.5 What, in your opinion, should they receive and why don't they?

B.5.1 More effort should have been put into engaging with my cared for person to win their trust. Services have always said as my cared for person won't engage, they can't engage, but they have never tried hard enough. Listen to the carer, take action in a more pro-active manner, try talking more, both to the carer & the person with mental health problems, in order to win their trust & treat them with respect & dignity. Take some time & then reap the results of taking that time.

NB: My cared for person has been isolated in their room for over 11 years, this is

despite requesting help on several occasions (7 at least); each time no appropriate help has been forthcoming due to the MH service's insistence that if my cared for person won't engage, they can't engage. There follows countless excuses & delays whenever I have initiated contact, always leading to no avail & causing a great amount of stress to myself as a carer. Above anything else my cared for person has lost 11 years of their life!

B.5.2 I don't know what my Son receives.

All he has is medication every three months & a yearly invite.

B.5.3 day centre with different therapies such as mindfulness, small discussion groups, activities, art, complimentary therapies, individual/group counselling, well-being/health/education sessions. They are unable to get there, depends how they feel, do not know what is available.

B.5.4 A stand-in carer from time to time.

B.5.5 My son has autism and is under the care of the neuro-developmental team at Yourhealthcare in Kingston. They are excellent.

B.5.6 When in a crisis support is very hard to find. I get passed from pillar and post no one wants to take responsibility often or not I'm left to deal with his mental health own my own. Any help with mental health, I would and him accept.

B.5.7 It is the lack of support for carers who care for people who do not want to engage, that concerns me and no doubt several other families in the borough. Ideally (if he engaged with any services) our son (aged 24) should receive support with integration into society, with a link for us as his parents into the mental health support team.

B.6.a What is your experience of this care?

The following results were given:

Not specified	7
Fair	4

Good	3
Inadequate	4
Poor	1

B.6b Could you say more about your experience:

Eleven people gave further details of their experience, 7 at length.

B.6b.1 The care provided has been negligent at best and dangerous. A CQC investigation has confirmed this to be the case. There are clear and demonstrable breaches of MH legislation as well as breaches of equality act and health and social care act. The 'care' provided is woefully inadequate and has resulted in avoidable hospitalisation and trauma. The attitude and behaviour of the trust has caused trauma both to the patient and the family. The trust is actively and demonstrably dishonest in their communications and seem to be without any accountability.

B.6b.2 There is no regular follow-up to monitor the mental state of the person I care for, so that he could get into serious difficulties if he was not being observed by his family, and it is always necessary to request a referral by the GP before he even gets a telephone consultation from a psychiatrist. He is then immediately discharged back to the GP and it is left to the family to see if his medication seems to keep him stable, which is obviously an unsafe situation.

B.6b.3 There is no follow up once the patient is discharged from the hospital. Mental illness is not an illness which can be treated with just medicine only. It requires not only follow up but must also include rehabilitation

B.6b.4 The support and care over the last nine years has been intermittent not continuous. My husband has been "referred back to GP" many times whilst still needing the support of a Mental Health Team. It is extremely difficult to get referred back into Secondary care. The criteria needing to be met would appear to be that the person has to either be a danger to him or herself, a danger to others, or suicidal. I would add that "referred back to GP" is an euphemism for "referred back to Carer!" There is very little, if any, support for the person's Carer. The so-called

Triangle of Care doesn't seem to be working in practice.

B.6b.5 My son attends the Tolworth hospital Clozapine clinic on a regular basis where he collects his medication and has a blood test. That is his only contact with support services. I as his carer have had no contact with support services for almost 5 years. I don't know if my son has a support worker as neither of us have heard from support services in recent times.

This wasn't the case in the past as both my son and I were in regular contact with support services and had the contact details of his support worker. She moved on and nothing since.

In answer to question 5 I don't know if my son has a current care plan

B.6b.6 The care worker is tricky to get hold of and at times the dr is not available as often as needed. But on the whole I am satisfied with the care my son receives especially as he is in a Hestia house and has help there.

References from my son's care worker to the home treatment team have been wonderfully useful and I feel they are an essential part of the set up.. A great innovation.

Care has been difficult these last years but, I do feel people try to help

B.6b.7 My family member a good Care Coordinator who has been in place for many years, and maintains regular face-to-face contact.

B.6b.8 Difficult in beginning of illness but since stabilised, experienced good support.

B.6b.9 Support has been patchy and I think that resources are limited. Often mixed messages get given to us all.

B.6b.10 Sadly there has been a lack of continuing care. There have been multiple changes in professionals dealing with my husband over the last 9 years. He's been discharged back to GP (a euphemism for being discharged back to ME!) several times despite my writing to say I cannot with him cope alone and need support. Whatever happened to the Triangle of Care? It is extremely difficult to get back into Secondary Care once discharged. Only a serious crisis will enable

this. It is impossible to get in touch with allocated professionals by telephone when needed. On the last occasion, after a lengthy wait, I only managed to reach the Duty Officer, who promised to pass on my message, but I have not heard back. I feel alone. I need advice on what to do.

B.6b.11 Reviewing of medication is always very prolonged as understanding the side effects and the impact on the individuals recovery from an episode reverberates on the carer. Chasing appointments, trying to speak to Consultants and getting right support for the person I'm caring for can be time consuming and take over completely. Until there is a crisis help has been limited.

B.7 Does the person you care for have a current Care Plan?

Seven respondents replied yes to this, five replied no and seven didn't reply. One respondent included this following remark in the response from the previous question. "In answer to question 5 i don't know if my son has a current care plan"

B.8 Do you consider this Care Plan to be adequate?

This response was in the form of five stars and the 7 who replied yes to the previous question: 2 gave 5 stars; 2 gave 4 stars; 2 gave 3 stars and 1 gave 1 star.

B.9 Is any member of the MH Support Team at Tolworth Hospital in regular contact with you and/or the person you care for?

One respondent said that someone was in touch with both themselves and the one they care for, 8 respondents said that someone was in contact with the one they care for, 3 said that no one was in touch and 7 others did not reply.

B.10 Do you have the contact details of the staff member of the MH team who has prime responsibility for the person you care for? (eg Consultant Psychiatrist)

4 Respondents said yes, 8 said no and the other 7 did not reply.

B.11 Do you have the contact details of the staff member of the MH team who has routine responsibility for the person you care for? (eg Care Coordinator/ Key Worker)

4 Respondents said yes, 8 said no and the other 7 did not reply.

B.12 Are the person you care for and you invited to a review (at least annually) with a Consultant Psychiatrist and support team.

4 Respondents said both were invited, 2 said only the person cared for, 6 said neither and the other 7 did not reply.

B.13 Has the level of support received been consistent over time, particularly during this period of the pandemic? (1 to 5, 5 being best)

1 - 4

2 - 3

3 - 2

4 - 1

no reply - 7

B.14 How would you expect the level of support (with or without the pandemic) to be improved?

11 people responded to this with the following comments:

B.14.1 "Proper treatment based on the individual patients actual needs should be put in place. Honesty and proper communication from trust. Faster response to concerns raised. Carers to actually be valued rather than tick box policies that aren't followed through."

B.14.2 "He should be seen at least annually for a review to ensure things are not getting worse."

B.14.3 "As said in Q 4" - this referred to there being no follow up once the patient is discharged from the hospital.

B.14.4 "Regular reviews."

B.14.5 "It is surely a basic requirement of M.H care for both the carer, and the person he cares for to have regular contact with support services, and to have the contact details of the support worker and or team."

B.14.6 "More regular apptmt with the consultant"

B.14.7 "There has been no difficulty with the level of support"

B.14.8 "More consistent care between the teams"

B.14.9 "More knowledge about activities and support in the local community that are for everyone. Better communication."

B.14.10 "A carer needs to be able to easily get in touch with the psychiatrist and care co-ordinator and guidance and advice. The telephone system at Tolworth Hospital needs reviewing."

B.14.11 "Remind the support staff that Carers at time are drained and exhausted."

15. Have your own Carer needs been assessed at any time?

5 Respondents said yes, 7 said no and the other 7 did not reply.

16. When was your last Carers' Assessment?

3 Respondents answered this: 14/03/2010, 03/03/2015, 05/03/2021

17. Do you feel that your own needs have significantly increased since your last Carers' Assessment?

Of these 3, 2 replied Yes and 1 replied No. The 2 who did not supply a date also replied No.

18. Are there any other relevant details around the MH Support Team services you would like to bring to our attention?

The following 13 responses were given:

B.18.1 "The CQC has found that the trust is treating without consent since nearest relative/attorney actively excluded from ward rounds. On discharge, 117 care plan is not properly put in place and appropriate support is denied. The RST and HTT are not fit for purpose, relying on policy and protocol, whilst ignoring safeguarding and individual need. We are currently not safe. Appropriate treatment, such as therapy and OT is either denied or has very long waiting lists. Information on records is frequently incorrect. Professionals tend not to read patient notes prior to review meetings, care plans are not reactive and appropriate as a result."

B.18.2 "In 2022, with the long standing slogan of 'time to change, time to talk', KMHT should have by now moved on with the times & on from the old style MH practices of 100 years ago! It is apparent that still the 'so-called services' predominant answer is to section or do nothing.

There is the latest talk of open dialogue' (from Finland) but like everything else it would appear to be all talk so far & no action; yet this innovative & promising method could have so much more potential. There is a saying 'a stitch in time saves nine' - if prevention was the priority rather than waiting for for a crisis to happen it would save not only so much money, but people's lives, which is paramount. Why do the mental health teams always wait for crisis? Why not be pro-active& pre-empt crisis altogether?

The last occasion I asked for help was in early October 2021 & despite one safeguarding SW visit in late October, no one came back, despite chasing on numerous occasions for a social worker to come out on a further visit (as promised by the initial 2x SWs, following allocation of a further SW). Finally towards the end of January 2022 someone was talking of arranging a visit, but by then it was far too late, 3 1/2 months too late. To explain, in late October the first two SWs promised to come back to visit, so this was incredibly damaging making a promise & breaking it, especially as my cared for person originally shut themselves off due to severe trust issues & through bullying. Trust & continuity should have been key here. I am now dealing with the situation myself as I am not prepared to take the detrimental effects of fighting for help any longer (over 11 years) as I absolutely have to protect my own mental & physical health in order to remain strong in my caring role.

In 2018, the previous time of asking for help, a young student nurse (CPN) came out, along with the assessor, on the home visit assessment; how very refreshing she was! she listened, showed compassion & really wanted to help, but the senior MH person with her was quite the opposite & her subsequent report reflected her stern & uncooperative manner. She concluded in a written report that my cared for person maybe schizophrenic!!?? but that they (KMHT) couldn't engage as my

cared for person wouldn't engage. NB this so-called assessor didn't even meet or talk to my cared for person. So 'if' in fact Schizophrenia had been in anyway a true diagnosis (which indeed it was not) they abandoned their patient & walked away from such a serious diagnosis! Our GP was flabbergasted at the time. All it would have simply needed was trust to be built over time & several visits, not for them just to give up & walk away at the first hurdle.

Appalling conduct in the 21st century, especially when mental health services have predominantly been moved out from the psychiatric hospitals of the 20th century into the community (since the 1990s, so over 30 years now)!! The care was intended, by the year 2000, to be delivered within the community, but the reality is so often that there is no care! "

B.18.3 "The social groups for people with autism etc have been cut back far too much."

B.18.4 "Contacting the Carer giving them updates of progress etc would help as my Son receives letters & doesn't ever read them so he gives them to me."

B.18.5 "More help and support is needed for Carers who are on duty 24/7, and have to deal with and make decisions on challenging behaviour daily. Caring is a very lonely role."

B.18.6 "Over the time i have been a Carer (20 years +) the standard of secondary care seems to have dramatically deteriorated from what i experienced some years ago. At one time i was always invited to my son's annual review with hi psychiatrist. That hasn't been the case for some years now."

B.18.7 "The care worker to see the clients on a regular basis.. If they are doing well every 2-3months...but to see them to keep up with how they are doing. Cannot date our carer assessment as so long since. we had one but we are fine about that and do not need one at this time"

B.18.8 "Had limited support from ICOPE services"

B.18.9 "Over the years, there have been changes in Consultant Psychiatrists. The Trust needs to keep clients and Carers up-to-date with contact details of the current Consultant."

B.18.10 "No one to help or talk too always get passed to someone else and then dropped like a bag of coal."

B.18.11 "Although I did receive a Carer's Assessment six years ago, I have not had one recently."

B.18.12 "The mental health professional should seek the carer's input when making an assessment of their client's current mental health condition. When in a bi-polar manic period, the client is in an "alternative reality" and his or her perception of their current mental health condition cannot therefore be trusted. A carer is with their client 24/7 and I would have imagined a psychiatrist would have considered his or her input ESSENTIAL. The last report on my husband was inaccurate. Whatever happened to the Triangle of Care!?"

B.18.13 "Don't assume if patient lives with family that they don't need on going help. Listen to the carers if they raise concerns, especially if they oppose discharge from a service ie Home Treatment Team. Prevention of hospital admissions could have been avoided."

B.19 Although this survey is specifically concerned with the Secondary Community MH services in Kingston provided by SW London & St George's MH Trust, do you want to make any comments about other services?

B.19.1 "For myself as a carer:- Kingston Carers Network (KCN) - All staff both in adult & young carers sections have been excellent, always, throughout.

GP - Has been exemplary, going far above & beyond (equally dismayed & frustrated at secondary services).

KMHCF - Member since 2019 for support, advice & receiving MH notifications & what's on re' MH.

Kingston Council (RBK) - Adult Services Reception have each time been helpful when I have needed to contact recently.

SWLSTG Recovery College - Have offered high quality courses, have attended 260 hours worth in 2019.

Kingston Adult Education (KAE) - Action for Happiness Course (2019) - advertised through KCN

Hillcroft Women's College (RHACC) - Attended several H2020 free taster courses (2019-2020) - again advertised through KCN."

B.19.2 "Kingston Carers Network is very helpful for carers, but the individual with mental health problems in the community does not receive enough attention."

B.19.3 "It seems the mental health department is hit by funds and shortage of staff and in such circumstances the result will be not very good for the patient and more so for the Carer."

B.19.4 "Kingston Carers Network have been extremely helpful, especially through the regular peer group meetings. GPs are not sufficiently trained to diagnose and treat mental health problems. There should be a mental health professional at every GP surgery to oversee and navigate a patient through the whole process of getting mental health support. GP surgeries need to be provided with this information.

B.19.5 "Hestia and the housing and key worker very important and all the activities they provide Mind and Fircroft doing great work too.
A peer support team like the one in Sutton would be great as would a group for people suffering from schizophrenia.
More availability of volunteering opportunities for the clients this would help their self esteem greatly"

B.19.6 "Mum had attended Fircroft pre Covid, now the Organisation have no fixed residence; mum receive's sporadic telephone calls to offer support.
Receives a 5 minute telephone call from Age UK."

B.19.7 "Up until Covid, Hestia provided a varied programme of activities, which my family member enjoyed. There should be more social activities provided by a range of organisations, not necessarily specific to MH."

B.19.8 "Kingston Carers' Network has been excellent but sadly has had some of its finance taken away by Kingston, including the costs of the lady who ran the dementia group."

B.19.9 "Any help to deal with mental health and to be listened to. To be able in a crisis get help quickly in passed been told no help you can go to the other side of London that's not good enough when it's needed , you need help within our own area"

B.19.10 "No - the individuals we have encountered in the past have all been professional but the parameters of what can be offered (i.e. to people who don't engage) are limited. It is the support in getting the person to make that first step, that is lacking."

B.19.11 "Kingston Carers Network have been very supportive."

B.19.12 "Balance, Asperger's service could have a contact list of all adults diagnosed with ASD and send out a news letter much like KCN does to carers. It gives the client the opportunity to be kept up to date."

20. How did you hear about this survey.

17 respondents heard directly from KMHCF, 1 from social media and 1 from Kingston Carers.

21. If you would like to enter the Prize Draw, please give your name and email address

10 respondents chose to join the prize draw.

APPENDIX C – Terminology

Primary Care - Health care supplied by GPs

Secondary Community MH services in Kingston: - services supplied from SW London & St George's Mental Health Trust

CQC - Care Quality Commission

KCN – Kingston Carers Network

Triangle of Care – A policy of SW London & St George's Mental Health Trust to include carers in decision making

RST - Recovery & Support Team

HTT – Home Treatment Team

OT – Occupational Therapy

KMHT – (Kingston Mental Health Trust) means SW London & St George's Mental Health Trust

CPN – Community Psychiatric Nurse

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