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Contribution of Mental Health Service User Groups to Mental Health Services and Policy in Ghana – The Case of Mental Health Society of Ghana

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Master's dissertation in Mental Health Policy and Services

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DECLARATION

I hereby declare that this thesis is the result of my own work under the supervision of Prof.

Benedetto Saraceno and no part or its whole has been presented for award of a degree in this university of elsewhere

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DEDICATION

I dedicate this thesis to my children, Yeriba-Gbana Juliet Pearl, Korog Leonard and Tereyin Mettle.	

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LIST OF ACRONYMS AND INITIALS

BNGh BasicNeeds-Ghana

CBO Community Based Organisation

CSO Civil Society Organisation

GFD Ghana Federation of the Disabled

PHC Primary Health Care

IAPO International Alliance of Patient Organisations

MDA Ministry, Department, and Agency of government of Ghana

MMDA Metropolitan, Municipal and District Assemblies

MEHSOG Mental Health Society of Ghana

NGO Non-Governmental Organisation

PANUSP Pan-African organisation of Users and Survivors of Psychiatry

SHG Self-Help Group of persons with mental illness or epilepsy and

their primary care-givers

UNCRPD United Nations Convention on Persons with Disability

WHO World Health Organisation

ABSTRACT

This study sought to document the perspective(s) of mental health users and care-givers associations in community mental health service provision and their role and contribution as it was perceived by a number of key informants including the mental service users and care-givers themselves. The specific case of the Mental Health Society of Ghana (MEHSOG) was the focus of this study. A case study approach was used to with Focus Group Discussions and Key Informants Interviews being the data collection tools that were used. These data collection tools were complemented by participant observations and review of documents of the MEHSOG and the various community self-help peer support groups that make up the national association.

The study revealed that mental health service users and their care-givers constitute an important stakeholder group in community mental health service provision and development of policies that factor in the needs and rights of persons with mental illness or epilepsy. MEHSOG's involvement in mobilising members and education families to come forward with the relations with mental illness to benefit from treatment services were well made a significant impact in improving the health and participation of service users and their primary carers in family decision-making processes and in community development processes. Service users, on benefiting from treatment, and primary care-givers, on becoming freer and less burdened with the responsibility of care, move on to engage in secure livelihoods activities, which enhanced their status in their families and communities. The advocacy MEHSOG members undertook in getting the mental health Bill become Law was also noted as significant development that was realised as a result of active involvement of service users in calling for a new and inclusive mental health legislation for Ghana.

Enabling factors and opportunities that enabled mental health service users and primary care-givers of people with mental illness to actively support community mental health service provision and policy development is with the vibrant civil society presence in Ghana, particularly

the disability movement, and earlier efforts by NGOs in mental health in Ghana long-side mental

health professionals to have a new law in mental health. A number of challenges were also noted

which were found to limit the extent to which mental health service users can be influential in

community mental health service provision and policy development. Key among them was the

social stigma against mental illness and people with mental illness or epilepsy and their primary

carers. Stigma has affected perceptions, analyses of the general public, especially health

practitioners and policy authorities that it has affected their prioritisation of mental health issues in

policies and programmes. Another challenge was the poor infrastructure available to support

enhanced mental health care services that ensure mental health service users remain in a good state

of health and wellbeing to advocate for themselves.

The recommendation from the study is that mental health service user movements are

important and need to be supported and encouraged to play their role as persons with lived

experience to inform organisation and provision of mental health services as well as design and

implementation, monitoring and evaluation of policies and programmes.

Key words: Mental health, Users, Participation, Policy, Services

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RESUMO

Este estudo procurou documentar a perspectiva (s) dos utentes de saúde mental e das associações de prestadores de cuidados sobre a prestação, o papel e a contribuição de serviços de saúde mental da comunidade tal como foram percebidos por um número de informadores-chave, incluindo os utentes do serviço mentais e os próprios prestadores de cuidados. O caso específico da Sociedade Saúde Mental do Gana (MEHSOG) foi o foco deste estudo. O modelo foi o de um estudo de caso, utilizando discussões de grupo e entrevistas com informadores-chave como instrumentos de recolha de dados. Estas ferramentas de colheita de dados foram complementadas por observações dos participantes e pela revisão de documentos da MEHSOG e dos vários grupos de apoio da comunidade de auto-ajuda que compõem a associação nacional.

O estudo revelou que os utentes dos serviços de saúde mental e seus prestadores de cuidados constituem um importante grupo de partes interessadas na prestação de serviços de saúde mental da comunidade e no desenvolvimento de políticas que tenham em conta as necessidades e os direitos das pessoas com doença mental ou epilepsia. O envolvimento da MEHSOG promove a mobilização de membros e famílias relacionadas com a doença mental de beneficiar de serviços de tratamento bem organizados com um impacto significativo na melhoria da saúde e da participação dos utentes dos serviços e seus prestadores de cuidados primários em processos de tomada de decisão da família e na comunidade processos de desenvolvimento. Os utentes dos serviços por beneficiarem de tratamento, e os prestadores de cuidados primários, por se tornarem mais livres e menos sobrecarregados com a responsabilidade de cuidar, podem passar a envolver-se mais em atividades que melhoramo seu estado, o de suas famílias e das comunidades. A advocacia dos membros da MEHSOG para conseguir que a "Mental Health Bill" se transforme numa Lei foi também um desenvolvimento significativo resultante da participação ativa dos utentes do serviço em chamar a atenção para uma nova e inclusiva legislação de saúde mental para o Gana.

Entre os fatores e oportunidades que permitiram aos utentes dos serviços de saúde mental e

aos prestadores de cuidados primários de pessoas com doença mental apoiar activamente a

prestação de serviços de saúde mental comunitária e o desenvolvimento de políticas conta-se a

contribuição da sociedade civil do Gana, particularmente o movimento da deficiência, e os esforços

anteriores de ONGs em saúde mental e dos profissionais de saúde mental para ter uma nova lei em

saúde mental. Observámos um certo número de desafios e barreiras que actuam de forma a limitar a

influência dos utentes dos serviços de saúde mental na provisão da saúde mental comunitária e no

desenvolvimento de políticas. Entre elas o estigma social contra a doença mental e pessoas com

doença mental ou epilepsia e seus cuidadores primaries é um factor chave. O estigma tem alterado a

percepção e as análises do público em geral, especialmente dos profissionais de saúde e das

autoridades políticas afetando a priorização dos problemas de saúde mental nas políticas e

programas. Outro desafio foi a deficiente infra-estrutura disponível para apoiar serviços de saúde

mentais que assegurem aos utentes permanecerem em bom estado de saúde e bem-estar para serem

advogados de si próprios.

A recomendação do presente estudo é que os movimentos de utentes dos serviços de saúde

mental são importantes e que eles precisam de ser apoiados e encorajados a desempenhar o seu

papel como pessoas com experiência vivida para contribuir para a organização e prestação de

serviços de saúde mental, bem como para a implementação, monitorização e avaliação de políticas

e programas.

Palavras-chave: Saúde mental, Utentes, Participação, Política, Serviços

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RESUMEN

Este estudio trata de documentar la perspectiva (s) de los usuarios de salud mental y las asociaciones de cuidadores en la prestación de servicios de salud mental de la comunidad y de su papel y la contribución, ya que fue percibido por una serie de informantes clave, incluyendo los usuarios de los servicios mentales y los propios cuidadores. El caso específico de la Sociedad de Salud Mental de Ghana (MEHSOG) fue el tema central de este estudio. Un estudio de caso se utilizó para con grupos focales y entrevistas a informantes clave son las herramientas de recolección de datos que se utilizaron. Estas herramientas de recolección de datos se complementaron con observaciones participantes y revisión de los documentos de la MEHSOG y los diversos grupos de apoyo de la comunidad de autoayuda que componen la asociación nacional.

El estudio reveló que los usuarios de servicios de salud mental y sus cuidadores constituyen un grupo de interés importante en la prestación de servicios de salud mental de la comunidad y el desarrollo de políticas que toman en cuenta las necesidades y derechos de las personas con enfermedades mentales o epilepsia. La participación de MEHSOG en la movilización de los miembros y familias de educación a presentar las relaciones con enfermedad mental para beneficiarse de los servicios de tratamiento estaban bien tuvo un impacto significativo en la mejora de la salud y la participación de los usuarios de los servicios y sus cuidadores primarios en los procesos de toma de decisiones de la familia y en la comunidad los procesos de desarrollo. Los usuarios del servicio, en la que se benefician de tratamiento, y los cuidadores primarios, al hacerse más libre y menos cargado con la responsabilidad de la atención, pasan a participar en actividades de medios de vida seguros, que mejoraron su estado en sus familias y comunidades. Los miembros de la abogacía MEHSOG comprometieron a conseguir el proyecto de ley de salud mental se convierta en ley también se señaló como importante desarrollo que se realizó como resultado de la

participación activa de los usuarios del servicio para pedir un nuevo e incluyente legislación de

salud mental para Ghana.

Factores y oportunidades que permitieron a los usuarios de servicios de salud mental y los

cuidadores principales de personas con enfermedad mental para apoyar activamente la prestación de

servicios de salud mental de la comunidad y el desarrollo de políticas de Habilitación es la

presencia vibrante sociedad civil en Ghana, en particular el movimiento de la discapacidad, y los

esfuerzos anteriores por ONG de salud mental en Ghana-secundarios a largo profesionales de salud

mental para tener una nueva ley en materia de salud mental. Una serie de retos también fueron

señaladas que se encontraron para limitar el grado en que los usuarios de servicios de salud mental

pueden ser influyente en la prestación de servicios de salud mental de la comunidad y el desarrollo

de políticas. Clave entre ellos era el estigma social contra la enfermedad mental y las personas con

enfermedad mental o epilepsia y sus cuidadores primarios. El estigma tiene percepciones afectados,

los análisis de la población en general, especialmente los profesionales de la salud y autoridades

políticas que ha afectado su priorización de problemas de salud mental en las políticas y programas.

Otro desafío fue la deficiente infraestructura disponible para apoyar los servicios de atención de

salud mental mejoradas que aseguran a los usuarios de servicios de salud mental permanecen en

buen estado de salud y bienestar para abogar por sí mismos.

La recomendación del estudio es que los movimientos de los usuarios de servicios de salud

mental son importantes y necesitan ser apoyados y animados a desempeñar su papel como personas

con la experiencia vivida para informar a la organización y prestación de servicios de salud mental,

así como el diseño y la implementación, seguimiento y evaluación de políticas y programas.

Palabras clave: Salud Mental, Usuarios, Contribución, Política, Servicios

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CHAPTER ONE

BACKGROUND TO THE STUDY

1.1 Introduction

Mental health service user organisations have been identified to be useful entities to support efforts needed to improve the prevailing mental health systems for quality mental health service delivery (WHO, 2001, Lancet Global Mental Health Group, 2007). This they will do by being actively involved in mental health service user mobilisation, service organisation and planning and policy development. Such involvement significantly contributes to accessible and equitable mental health services that meet the needs of persons with mental disorders, and relief burdens of primary care-givers and families. It also promotes socio-economic development and reduction of poverty. Whilst the emergence, presence and influence of mental health service users in Western Europe and North America have been well documented (Campbell, 1993, Crossley, 1999, 2001), the spread of mental health user organisations in Africa have been very limited and most probably the reason why there is little literature on service user associations or movements. For example, Kleintjes (2013) in her study of mental health user groups in Africa engaged in mental health advocacy found only ten countries with user/consumer movements. This means the involvement and contribution of mental health service user and/or carer movements in mental health policy and service development in Africa is likely to be less recognised and appreciated. This notwithstanding, there is also ample evidence that the few available user associations in the respective countries have actively supported mental health policy and services planning and implementation, making their membership recognised as key stakeholders in mental health.

A national user association that has recently emerged in Ghana and actively involved in mental health service and policy advocacy of the country is the MEHSOG. MEHSOG has

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within four years, since it was formed, demonstrated the vital role of service user and carer groups in mobilising and promoting mental health care services and influencing policy in favour of people with mental illness or epilepsy and their primary care-givers and families. This study seeks to reflect on the emergence of MEHSOG into Ghana's mental health scene and its contribution to advocacy for improved mental health services for people with mental disorders and general reform of the mental health system of Ghana, as part of contributing to encourage active participation of service users and primary care-givers in development processes. It will document successes and challenges in the journey of the associations and the prospects for services users as advocates in mental health service and policy issues

1.2 Popular participation, democracy and good governance

Popular participation in community development can be said to be a human instinctive socio-cultural trait of most human being (Ghanaweb, 2014). Beyond this fact, documented popular participation of organised groupings in national socio-economic and political development in Ghana can be traced to colonialism and the struggle for political independence (Bonye, Aasoglenang, Owusu-Sekyere, 2013). Following establishment of the Department of Community Development of Ghana in the 1948, organised groupings of people to support development, particularly infrastructure development to realise modernisation from the less development rural and primitive settings became more formalised (Bonye, Aasoglenang, Owusu-Sekyere, 2013). In Ghana the promotion of people's participation in national and community socio-political and development gained further impetus in the military revolutionary regimes of the 1970s through to the early 1990s. During these periods citizens were encouraged to be actively involved in discourse and activities that very much affect them. The local government and decentralisation of governance to increase citizen participation took centre-stage towards the late 1980s and by 1992 when the fourth republican constitution came into force all the identifiable groups that

were part of consultative assembly were established and actively worked to contribute to community and national development and remain relevant. The coming into being of democracy which ushered in party politics also came in its wake a consciousness to bring about democratic governance. This also brought along the development of interest groups and pressure groups to ensure their needs were catered for and rights guaranteed within the political parties and nationally. Decentralisation particularly thrust the responsibility of development efforts of communities to the communities themselves with the state being a facilitator creating the enabling environment for development. Relatedly, the steady devolution of responsibility of the state as sole provider of public good and service to promotion of public-private-partnership where citizen groups and businesses are to play active roles in provision of public goods and services saw the emergence of NGOs and CSOs to both contribute to such development processes, but also more importantly to claim and protect their needs and interests (Bonye, Aasoglenang, Owusu-Sekyere, 2013). Over the last three or so decades in Ghana, therefore, there has been an active promotion and development of citizen groups to take advantage of the democratic dispensation to fully be involved and influence public policies and decision-making. More significant has been the emergence of citizen groupings along disability and/or health conditions.

At the health front, good is very necessary for achieving health equity and bringing about a health population and total development (WHO, 2011). Good governance has been recognised as be key in bringing about improved health to the extent that the during the WHO organised World Conference on Social Determinants of Health "better governance for health and development" was vital to realising better health status of populations by governments ensuring "transparent and inclusive decision-making processes that give voice to all groups and sectors involved ... with specific attention to vulnerable groups and high-risk areas" to promote global health and reduce health inequities (WHO, 2011).

1.3 User movements and Mental health user movements

Globally, emergence of user movements have been traced to such key developments as the "...the Enlightenment, and the subsequent French and American Revolutions. The development of democratic government in several Western countries ... and ... the Universal Declaration of Human Rights (1948)..." as significant epochs within which ideas of inclusion of ordinary citizens was popularised (Tambuyzer, and Van Audenhove, 2013).

Crossley (1999) in providing his theoretical approach to his article that traced and explained the emergence of the mental health user movement in Great Britain, and citing and quoting Melucci (1986, 1996), Bryne (1997) and Boaudien, describes "Movements, as ... not 'subjects', 'agents' or 'things'. They are networks, often 'submerged networks', of dispersed interaction. But they are more than this too. They manifest as specific transformations in ways of perceiving, thinking, speaking and acting, and in forms of social relationship; that is, they manifest as transformations in social practice" (648). Crossley, further adds that , the use of the term 'user' rather than 'patient' ... is itself both an indication and a manifestation of 'movement' within the sphere of mental health practice.

In 2001, the WHO reinforced the place of user movements in mental health care policy and services, calling for active involvement of service users in community mental health (WHO, 2001, 2014). This was in recognition of the key role mental health service users and their primary carers and families play in mental health service planning and provision.

The earlier known service user movements in Ghana could be traced to the disability associations. Even though not strictly medical in nature in terms of the disability people have, disability peoples organisations rallied around similarity of their conditions first and then ultimately established the Ghana Federation of the Disabled (GFD). For example, the Ghana

Society of the Blind (GSB), established in 1951 was an off-shoot of the Commonwealth Society of the Blind, now SightSavers, and predates the GFD. It is should be noted that GSB has evolved into the Ghana Blind Union (GBU) being the amalgamation of the GSB and the Ghana Association of the Blind (GAB) (GAB, 2013). This also could be said to have served as motivation for the emergence of national mental health association in Ghana.

1.4 Mental health and scaling up of services

Having established that neuropsychiatric disorders significantly contributes to the global burden of disease and disability adjusted life years of populations, the need to scale-up mental health services for the populations, especially in low and middle income countries has been effectively articulated by the (WHO 2001, 2010, 2014, Saraceno, van Ommeren, Batniji, Cohen, Gureje, Mahoney, Sridhar, Underhill, 2007). Among key recommendations for scaling up of mental health services have been for increased advocacy and influencing of government and policy authorities and key identified stakeholders or players to bring this about are organised persons with mental illness or epilepsy and their primary care-givers and families (Tambuyzer, Van Audenhove, 2013; Kleintjes, Lund and Swartz, 2013, Saraceno et al, 2007).

For mental health users association, their involvement in scaling mental health services will be important many ways. User associations will serve as important rallying points to mobilising persons with mental health service needs for treatment, serve as lay community workers, especially human resource constrained settings, to support organisation and delivery of mental services and use their numbers to challenge the social stigma and discrimination so much associated with mental disorders. Perhaps, the most important role and contribution to scaling up services will be their advocacy and activism roles and responsibilities (Saraceno et al, 2007). User associations enable emergence of role models to lead in advocacy in mental health to engage. As Saraceno et al (2007) recommend, "Population-wide progress in access

to humane mental health care will depend on substantially more attention to politics, leadership, planning, advocacy, and participation." This means advocacy, lobbying and influencing are necessary and involvement of service users as consumers and citizens is paramount to realising the policy changes and service optimisation required for mental health and health of populations for that matter.

1.5 Mental Health Society of Ghana

Mental Health Society of Ghana (MEHSOG) was established in 2008 by the coming together of core group of 120 community self-help user support groups (SHGs) of persons with mental illness or epilepsy and their primary carers. The SHGs emerged from activities of BasicNeeds-Ghana and were operating for close to three years before the coming into being of MEHSOG. Following a delegates conference in October, 2008 the MEHSOG was and a draft constitution was adopted and approved, which paved way for the formal registration of the association in 2009 (Yaro and de Menil, 2010). The purpose of the MEHSOG is "promote human rights, disability rights and socio-economic development of people with mental illness or epilepsy at the national level. It seeks to engage national authorities to ensure needs and rights of mentally ill people are effectively addressed in national policy initiatives" and programmes (Yaro, and de Menil, 2010, p. 75).

The organisation has a three-tier structure with the Annual General Meeting (AGM) of national delegates' conference being the highest decision-making body of the organisation. Members of the national delegates' conference are elected representatives of district associations of SHGs, which are the collection of SHGs of a given political and administrative region of Ghana. The community SHGs are the basic unit of the association from which the AGM draws it mandate. A typical SHG has an average of 25-30 members. As at December, 2012 MEHSOG had a total membership of 17,800 members (MEHSOG, 2013; Kofie, 2013). MEHSOG has an elected National Executive Committee (NEC). This is made

up of five members of President, Vice President, Treasurer and Vice Treasurer, and a coopted member, as well as elected representatives for every region that has SHGs affiliated to the umbrella body. As at November 2013, the NEC was an 11-member one, in addition to the Executive Secretary, who is appointed and has no voting rights. The Executive Secretary is the administrator of the national secretariat based in Accra, Ghana. The Executive Secretary is assisted by an Administrative Officer and they together service the NEC of MEHSOG.

MEHSOG has an independent advisory body of a varied mix of experts that support the overall governance of the association. This body is purely advisory their recommendations, advice and suggestions as approved or otherwise at the AGM, through the National Executive Committee.

1.6 Conclusion

This chapter introduces the need for the study on the contribution of user associations in mental health service delivery and policy development using the case of MEHSOG in Ghana. It provides basis for involvement of mental health service user associations, especially as consumers of mental health services, in mental health policy and service planning and implementation. Establishment of the contribution of mental health global burden of disease, and the need to scale up services to address the inequalities and inequities in mental health service delivery, and justification of democratic dispensation and health good governance together makes it imperative to have involvement of citizen groups in health and development processes.

The subsequent chapters will review related literature on the subject of role and involvement off user associations in mental health policy and service, methodology for the case study, and presentation of findings from the field study. The final chapters discuss the findings from the field study draws conclusions from the findings, making recommendations for implementation ad future research

CHAPTER TWO

REVIEW OF LITERATURE

2.1 Introduction

Ever since it was established that mental disorders significantly contributed to the global burden of disease, recommendations and strategies proffered to address the burden of disease and treatment service gap have included active involvement of service users and families (WHO 2001; WHO 2010).

Mental health service user organisations have been identified to be useful entities to support efforts needed to improve the prevailing mental health systems for quality mental health service delivery (Kleintjes, Lund, Swartz, Flisher & & the MHAPP Research Programme Consortium, 2010). Mental health service users can make this possible by being actively involved in service organisation and policy development. Such involvement significantly contributes to accessible and equitable mental health services that meet the needs of users and their families, promote socio-economic development, and reduction of poverty. Despite the importance and presence of mental health service user organisations in the world, their presence and spread in Africa have been limited (Kleintjes, Lund, Swartz, Flisher & the MHAPP Research Programme Consortium, 2010; Yaro & de Menil, 2010; Katonoka, 2007; Underhill, 2005). This means the involvement of mental health service user and/or carer movements in development of mental health services in most countries in Africa have largely been missing.

This notwithstanding, the few that have emerged have played highly significant roles in the development and implementation of mental health policies and services in their respective countries (Kleintjes, Lund, Swartz, Flisher & the MHAPP Programme Consortium, 2010; Yaro & de Menil, 2010; Katonoka, 2007; Underhill, 2005). A national

user association that has recently emerged in Ghana and actively involved in mental health service and policy advocacy of the country is the Mental Health Society of Ghana (MEHSOG). MEHSOG has within four years, since it was formed, demonstrated the vital role of service user and carer groups in mobilising and promoting mental health care services and influencing policy in favour of people with mental illness or epilepsy and their primary care-givers and families.

This study seeks to reflect on the emergence of MEHSOG into Ghana's mental health scene and perspectives of its contribution to mental health service and policy advocacy in Ghana. This is part of contributing to and encouraging active participation of service users and primary care-givers in health and general development processes. It will document perspectives of the successes and challenges in the journey of the association and the prospects for service users as advocates in Ghana's mental health service and policy issues.

2.2 Background to service user movement and their involvement in mental health care services and policies

Mental health service user and/or carer advocacy traces its roots and take inspiration from civil rights movements of African Americans and women civil rights movements as well as those of people with physical disabilities and consumer rights protection organisations of the 1960s and 1970s (Bluebird, n.d.; Reaume, 2002; SAMHSA ADS Center, 2009). The period of de-institutionalisation of the large lunatic asylums (mental hospitals) of Western Europe in the mid-1960s also significantly contributed to the emergence of service user movements and activism for mental health service and policy reform, as ex-inmates established peer support groups to share experiences during their admission in the mental hospitals and to provide emotional support to one another after discharge from the mental institutions (Bluebird, n.d., Reaume, 2002). Crossley (2005) accounts for the growth of the mental health social movement by tracing the trajectories within the psychiatric field that

significantly shaped mental health user associations' involvement in and influence of mental health policy and service to namely; "the anti-psychiatric trajectory, the survivor trajectory, the civil rights trajectory and the paternalistic trajectory. Although the civil rights and paternalistic trajectories are, arguably, the oldest of these trajectories, the contention surrounding mental health at the start of our period, the 1960s was most clearly marked by the emergence of antipsychiatry" (p 554).

These trajectories have resulted in mental health social user movements being described variously as 'patients',' 'consumers' or 'survivors' movements (Crossley, 2005; Speed, 2006). Reaume (2002) describes these terms of 'patients', 'consumers', and 'survivors' as providing the historical transition of terminology associated with mental illness which has travelled through the years of mental health, without reference to the development of diagnostic categorisation of mental illness. According to Speed (2006), the 'patient' comes across as a passive recipient of care accepts their diagnosis and to comply with prescribed treatment; the survivor resists and rejects any psychiatric diagnosis and is not obliged to accept treatment; whilst the consumer neither accepts fully nor reject fully their diagnosis but wanders between the other two maximising their benefits. These however operate variously to bring about improved access to basic services [mental health services inclusive] and exercise of basic human rights.

In the last two decades, the increasing recognition of mental health as a public health issue and the particularly disproportionate contribution of mental disorders to the global burden of disease have increased calls for participation of service users and carers, families and communities in the organisation and delivery of mental health service and policy development (WHO, 2001; Funk, Minoletti, Drew, Taylor, & Saraceno, 2005; Saraceno, Freeman, & Funk, 2009). Among the ten set of far-reaching recommendations for improving mental health that WHO made in its 2001 World Health Report, which was dedicated to

mental health, particularly with regards eliminating stigma and discrimination associated with mental disorders and increase in access to mental health services, was that "communities, families and consumers should be included in the development and decision-making of policies, programmes and services (p xi). This should lead to services being better tailored to people's needs and better used. In addition, interventions should take account of age, sex, culture and social conditions, so as to meet the needs of people with mental disorders and their families are effectively met (p 111).

Involvement, participation and influence of mental health service user and/or carer social movements have thus since become a key ingredient in mental health service and policy development processes (Bass, Bornemann, Burkey, Chehil, Chen, Copeland, et al, 2012; Funk et al 2005, Pinfold 2000; Simpson & House 2002; WHO, 2008, 2010). Recognition and empowerment of service users and carer groups to promote their own health, influence health services and actively engage with health professionals and other organisations have been embraced and effectively operated in Western Europe, north America and the Australia regions (Battam and Johnson, 2009; Crossley & Crossley, 2001; WHO, 2010). The WHO Regional Office for Europe has specifically developed and issued a strategy for user empowerment and participation in mental health service and policy (WHO, 2010).

In sub-Saharan Africa, mental health user associations emerged only around the early 2000s (Katontoka, 2007). Since then the space and activities of mental health service users and carer movements have been on the increase (Kleintjes, Lund, Swartz, Flisher, & The MHAPP Research Programme Consortium 2010; Yaro and de Menial, 2010; Kleintjes, Lund, Swartz, 2013). This however has been far and between. As at October 2011 PANUSP had listed some nine organisations identified as representative mental health service user movements from eight countries of sub-Saharan Africa being members or allies of PANUSP

– mental health society of Ghana (MEHSOG), being one of them (PANUSP, n.d.). These included, "MindFreedom Ghana, Mental Health Users and Survivors of Psychiatry of Kenya (USPK), Mental Health Society of Ghana (MEHSOG), Mental Health Users and Carers Association of Malawi (MeHCAM), Tanzanian Users and Survivors of Psychiatry (TUSPO), Mental Health Care Users Network of Zambia (MHUNZA), Ubuntu South Africa, National Organization of Users and Survivors of Rwanda (NOUSPR) and Mental Health Uganda" (PANUSP, n.d., p. 4).

The late emergence of mental health user movements in the sub-Saharan Africa is traceable to the long-held low prioritisation of mental health by most of the governments of sub-Saharan Africa. Fear and negative attitudes towards people with mental disorders translated into the engrained stigma and discrimination towards people with mental disorders have been identified to be the key blocks to adequate policies and plans to addressing mental health, for that matter active involvement of viable service user movements in mental health services and policies (Funk et al, 2005). According to Funk et al (2005), "government policies are often reflective of these fears and attitudes. It is sometimes presumed that government's primary responsibility with respect to people with mental disorders is to protect the general population from them. Furthermore, unlike people with other types of illnesses, people with mental disorders are often presumed to lack the capacity to make their own health care decisions," (p. 71). The disabling nature of mental disorders coupled with the stigma associated with them and the human rights abuses that most of people with mental disorders suffer increase the vulnerability which also significantly reduces their capacity to self-advocate (WHO 2001). As a result, conscious and deliberate efforts to grow user movement that can actively participate in promoting and protecting the rights of people with mental disorders and educating the general public as well as heath and development policy authorities and influence mental health policy reform is required (Funk et al, 2005). It is on

this basis that the Mental Health Society of Ghana (MEHSOG) was established with the active facilitation of BasicNeeds-Ghana (BasicNeeds, 2010).

MEHSOG has been actively functioning and operating for the past four years now. Considering its length of operations, it is a good time to assess its role as a mental health service user and carer organisation in mental health service and policy development.

2.3 Organisation of mental health services and the place of health service user organisations

Socio-cultural and religious practices and values, political, and scientific environments have shaped and continue to determine meanings of mental illness and the attendant treatment and care services (Saraceno, Freeman & Funk, 2009; Patel, Araya, Chatterjee, Chisholm, Cohen, et al, 2007; Angel & Williams, 2000). Historically, organisation and provision of mental health services have been based on longstanding cultural practices and values that placed mental illness as a condition in the spiritual realm significantly shaped the organisation and provision of mental health services (Patel, 1995, 2011, Razali and Yasin, 2008). Services were therefore inclined to interventions meant to remove the evil spirit(s), including exorcism, and such other practices meant to restore the imbalance caused by mental illness (Fabrega Jr, 1992; Saraceno et al, 2009). Others were left to their fate or punished (Saraceno et al, 2009). Crossley, (2005) also notes the early struggle of competing agents to establish monopoly of expertise, authority and rights of treatment, where in the 18th Century the growing 'madhouse' trade and the dominance of medical doctors over the rest, led to the creation of the large public asylums by the 19th Century.

Globally, formally structured mental health services have evolved from mainly custodial, institutionalised services, run exclusively from all other health care services, which persisted for close to five centuries, to largely integrated, rehabilitative and community

oriented services (Saraceno, Freeman & Funk, 2009; Funk et al, 2009). In such arrangement of exclusive custodial and institutional mental health services, service users had virtually no say in service organisation and provision. Over the years however, a broad spectrum of models of mental illness has emerged based on which services are developed to respond to not just the illness but also the social and psychological aspects of the illness conditions (WHO, 2003a, 2003b, 2003c). These models range from the bio-medical or disease model, to the social model, cognitive; behavioural and psychodynamic models (Bower, 2011; Harland et al, 2009). The biomedical model tended to dominate services for mental disorders as it developed from advancement in medical sciences. This is however now increasingly integrated with the other models (Patel, et al, 2007; Brocheler, Bergmann, & Schneider, 2009; WHO, 2009).

Another side of the evolution of mental health policy and practice has been the growing recognition of mental health as a public health phenomenon. According to Saraceno (2010), "mental health is relevant to PH [public health] not only because mental disorders are common but also because body and mind are linked and cause and outcome of physical illnesses are influenced by mental health status" (p 20). The place of mental health in public health significantly changed the nature of service organisation in most parts of the world. By viewing mental health as a public health issue, emphasis have been on preventing mental illness and promoting mental health (WHO, 1996). The appreciation of the public health aspects of mental health has made service organisation to move from being largely institution based to more integrated community care that encourage participation of both users, caregivers and families.

This has been well articulated by the WHO 'model of optimal mix of services for mental health care' to improve management of mental disorders and promotion of mental health (WHO, 2009; WHO n.d.; Saraceno et al, n.d.). According to the WHO, the model is

based on the principle that no single service setting effectively meets the mental health needs of populations. The model also emphasises support, supervision, collaboration, information-sharing and education across the different levels of care are essential to any mental health service system. The most important aspect of the model is that it also "assumes that people with mental disorders need to be involved, albeit to differing degrees, in their own [care and] recovery from mental disorders" (WHO, 2009, p 21). The model equally promotes human rights- based and community oriented approach to service organisation and delivery (WHO 2009; Patel et al, 2007).

Current approach to mental health service set-up and organisation is one of integrated community oriented services that involve users, families and communities in care and support (WHO, 2003). This approach has led to growing recognition of service users in mental health care service organisation and delivery (Funk et al., 2005; Saraceno et al., 2007).

Formal mental health services in sub-Saharan Africa were organised alongside the Lunatic Asylum laws, similar to what prevailed in the home countries of the colonialists (Mental Health Profile-Ghana, 2003, Saraceno, 2010). In Ghana for example, formal mental health was established by the 1888 Lunatic Asylum Ordinance following from which the first Lunatic Asylum (now known as The Accra Psychiatric hospital) was built in 1906 (Mental Health Profile – Ghana, 2003).

Despite epidemiological evidence establishing the poignant contribution of mental health to the global burden of disease and the treatment gap for mental disorders on one hand and the emergence of highly successful service set-up to address mental health treatment needs (WHO, 2001, 2003, 2008, 2009; Saraceno et al, 2005; Wang, Aguilar-Gaxiola, Alonso, Angermeyer, Orges, Bromet, et al 2007), countries of sub-Saharan Africa have largely lagged behind in developing mental health service policies and plans (WHO 2005, 2011; Ofori-Atta, Read, Lund, and MHAPP Research Programme Consortium, 2010).

Mental health care services in sub-Saharan Africa are characterised by poor accessibility, inadequate resource, and far from optimal organisation of services (WHO 2001, Funk, Jenkins et al, 2010). Most people with mental disorders do not have medical care for their conditions. Many of mentally ill people and people with epilepsy and their families rely on traditional remedies and traditional healers for their mental health care service needs, (Armah, 2008; de Menil, Osei, Douptcheva, Hill, Yaro, and De-Graft Aikins, 2012; WHO, 2002). Three main barriers have been identified to explain the largely inadequate mental health policy and service of most of the sub-Saharan African countries (Saraceno, van Ommeren, Batniji, Cohen, Gureje, Mahoney, Sridhar, Underhill, 2007; Saxena, Thornicroft, Knapp, Whiteford, 2007). These barriers include inadequate political will and/or commitment, inadequate resources, with the available resources being centralised (most at the central government level), over concentration on large specialised hospitals near to big cities; and the difficulties of integrating mental health care services into general health care at the primary health care level. In inadequate mental health leaders with adequate public health knowledge and experiences to lead transformation of the mental health system has also been a key barrier (Saxenna, Thornicroft, Knapp and Whiteford, 2007; WHO, 2008; Saraceno et al, 2009; Jenkins et al, 2010; Saraceno, 2010). The dearth of up-to-date mental health service policy and plans in many of the countries in sub-Sahara is also due to the relatively low participation of mental health service users and their families and communities in planning and delivery of services (WHO, 2008). Social stigma associated with mental illness hugely accounts for this (WHO 2001; Barke, Narko, Klecha, 2011).

Service organisation best meets the needs of the population when there is active advocacy and participation in processes to developing the services. This is even more important as mental health services and policies are evolving from highly specialised distinct

system of health care to a more integrated, community based one (WHO, 2003, 2008, Battam and Johnson, 2009).

2.4 Selected cases of user-led advocacy

In Africa, the emergence of disability and mental health service user groups saw the establishment of the Pan-Africa Movement of Users and Survivors of Psychiatry (PANUSP), now known as the Pan African Network of People with Psychosocial Disabilities (PANUSP, 2011). Advocacy efforts of established user movements have centred around improved treatment and rehabilitation, housing, employment and education, and general personal and human rights (Battam & Johnson, 2009; Harrington, 2009). The World Network of Users and Survivors of Psychiatry (WUSP) position itself as a human rights advocacy organisation, a global voice of and for people who use mental health services and/or have survived psychiatric treatment and abuse (http://www.wnusp.net/). The WUSP prides itself with the development and coming into force of the Convention on Rights of Persons with Disability (CRPD) and providing a global platform and identity to people with mental disorder (http://www.wnusp.net). Crossley, (2005) in his paper 'The field of psychiatric contention in the UK, 1960-2000' gives an account of the changes mental health user movements and related advocates influenced terminology related to mental health, as well as assumptions medical doctors, nurses, social workers, service users and their families made, their acceptance (or not) of role expectations of all agents concerned, awareness of and willingness to alternatives to traditional treatment regimes (p. 561). Reaume (2002) documents similar history of the influence of patient activism in North America on transition of nomenclature in psychiatry.

Davis et al (2010) also give a significant assessment of the contribution of parent advocates for families of children with serious mental illnesses. This has been significant in development of peer support to parents with children with severe and streamlined the

administrative and practice structures for peer support. According to Battam and Johnson (2009) service user groups together with NGOs in mental health in South Australia were instrumental in the development of the policy and programmes on housing. Much as they note that "the processes for 'consumer' participation within the mental health sector during the reform period meant that the consumer groups that did exist were largely an 'end' in themselves rather a 'means' to more empowering forms of participation.

In the sub-Saharan Africa scene, few active mental health service user movements are known to have been active in influencing the mental health policy and legislation, and service provision (Kleintjes, Lund, Swartz, Flisher, & The MHAPP Research Programme Consortium 2010; Kleintjes, Lund, Swartz, 2013).

2.5 Significance of the study

The growing recognition of the place of mental health service users and carer groups in mental health service and policy development in low and middle income has necessitated documentation of activities and contribution of service user and carer associations operating in sub-Saharan countries (Kleintjes, Lund, Swartz, Flisher, & The MHAPP Research Programme Consortium 2010; Kleintjes, Lund, Swartz, 2013). Whilst recognition of empowerment of service users to be involved in mental health service provision has been taken up in Europe, North America and the Australia regions, in sub-Saharan Africa there is limited literature on contribution to mental health service users to development and implementation of mental health policies are services in sub-Saharan Africa. The significance of this study therefore is to provide documentary evidence of perspectives of success stories in mental health service user advocacy in order to spur many other mental health service user and carer-led advocates and groups to continue to engage in influencing mental health service and policies and for wider user advocacy.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

The proposed research is a qualitative case study that will use key informant interviews and focus group discussions as the data collection tools. Qualitative case study approach is suitable for study of such phenomenon as the Mental Health Society of Ghana (MEHSOG) and their involvement in mental health policy and service advocacy.

3.2 Aim and objectives(s) the study

The focus on the Mental Health Society of Ghana is to build a case-study of that serve as reference support for similar entities that may emerge within sub-Saharan Africa and the West Africa sub-region in particular.

The objectives of the study are as follows:

- i. To document opportunities self-help groups of mental health service users and primary carers had to participate in and significant contributions they made to mental health service provision and the development of Ghana's mental health legislation
- ii. To assess the usefulness and influence of people with mental illness of mental health service users and carer groups in the development of Ghana's mental health legislation and services
- iii. To identify constraints that limit the participation and visibility of mental health service users and carer groups in community mental health legislation and services in Ghana

iv. To provide basis for further research into to report on opportunities and barriers to improving mental health care user participation in mental health-related policy development and implementation in Ghana

The question this study seeks to answer is 'what has been the contribution of the mental health service user and care-giver groups to mental health services and policy in Ghana?"

3.3 Study design

A qualitative case study methodology and methods will be used for this study. Baxter and Jack (2008) define qualitative case study as "an approach that facilitates exploration of a phenomenon within its context using variety of data sources" (p. 544). This type of research method allows for the answering of the 'why' and 'how' of issues and phenomena. It allows for understanding of particular situations from the perspectives, experiences and meanings of people and groups (Baxter & Jack, 2008; Bergen & While, 2000: Yin, 1999). Quoting Yin and Stake, proponents of qualitative case study methodology, Baxter and Jack explain that qualitative case study research is based on the "constructivist paradigm" which premises that "truth is relative and does depend on one's perspective. Constructivist paradigm thus recognises the "importance of the subjective human creation of meaning" but none the less does not reject completely the "notion of objectivity" (p. 545).

Qualitative case study research was suitable for this study as it sought to document those aspects of mental health policy and services, MEHSOG as an organisation of service users and carers have influenced, why they did it and how they went about doing that. The context of the study was therefore on the organisation for service provision for people with mental illness or epilepsy as well as the mental health (law) and social protection schemes of Ghana that MEHSOG had been involved in. Qualitative research allows for building a rich

data set about the views and perspectives of key stakeholders based on the unlimited, unrestricted and reflective information they will provide, the researcher will be open to multiple perspectives and unexpected responses provided by the participants (Poulin, 2007, Family Health International (fhi, n.d.). Baxter and Jack (2008) quoting citing Crabtree and Miller state that a notable advantage of the case study approach "is the close collaboration between the researcher and the participants, while enabling participants to tell their stories" (p. 545). Case study "emerges as an obvious option for ... a modest scale project based on an aspect of the work of the investigator (Rowley, 2002, p. 17).

3.4 Description of study participants

The research participants were a cross-section of members of MEHSOG and relevant stakeholders to provide information related to the research questions in one of the four regions of the northern-most regions of Ghana – Northern Region, Upper East Region, and Upper West Region and Greater Accra Region. The Executive Secretary of MEHSOG and selected leaders of the network of Self-Help Groups (SHGs) and their representative district associations of the SHGs that make up the MEHSOG. Other key informants were staff and management of BasicNeeds-Ghana, officials of the Ministry of Health (MOH) and Ghana Health Service (GHS), particularly Community Psychiatric Nurses (CPNs) and psychiatrists, officials of district assemblies of the Ministry of Local Government and Rural Development (MLRD), Department of Social Welfare (DSW) of the Ministry of Employment and Social Welfare and Members of Parliament (MPs) especially members of the select committee of Parliament on health. The research participants were 18 years and older, literate and non-literate. Risks of this study are minimal.

It is the expectation that study will make a significant contribution to a body of knowledge on scaling up mental health health services through broad-based and inclusive mental health policis and services in Ghana. As part of the IMMHPS course, this study was another contribution to mental health research outputs for for sub-Saharan Africa which has relatively few mental health research works compared to other parts of the world. By extension it sought to contribute body of literacture on service users globally. The results charts a path to deeper study into activities and influence of people's movements in mental health care policy and services development and for that matter scaling up of mental health services in resource poor settings. This was part of response to the inadequate capacity in research in mental health policy and services in Ghana and the researcher's pursuit to acquiring a degree in acquisition on that.

3.5 Sampling

Purposive sampling was used for this study. Purposive sampling is a non-random technique of selecting respondents to a research study (Tongco, 2007). Purposive sampling allows for a deliberate choice of respondents judged by the researcher to have knowledge and experience of the subject being studied and who are willing to provide such information (Palys, n.d.; Tongco, 2007). Purposive sampling was suitable for this study as it sought to document experiences and perspectives of member mental health service users and carers of the MEHSOG and other stakeholders in mental health service and policy advocacy in Ghana. Purposive sampling allowed for effective targeting of competent and reliable informants and assures quality of the data collected (Tongco, 2007; Byme, 2001; Taylor-Powell, 1998). The sample size for this study was therefore determined on the basis of theoretical saturation, that is, to the point that when new data provided by a respondent no longer bring in additional insights to the research question(s) (fhi, n.d.; Eisenhardt, 1989). This notwithstanding in each of the four regions, at least eight KIs and three FGDs will be undertaken. The KIs will be held for service users and a policy authority of the GHS/MoH and the District Assembly. The FGDs will be

held with the district associations of the SHGs and community mental health service workers, particularly from the GHS.

3.6 Data collection

Data for this study was collected through key informant interviews and focus group discussions. Key informant Interview (KI) is data collection tool used for collecting optimal information about experiences, perspectives and opinions of an individual judged to be knowledgeable of the issue under discussion (fhi, n.d.). It is a data collection tool that enables quality data to be obtained in a relatively short time (Marshall, 1996). This was beneficial to this study this kind to be undertaken. It allowed for a good cross-section of members of MEHSOG and relevant stakeholders to provide information related to the research questions. A total of four FGDs and ten KIs in four regions of Ghana were conducted on respondents known to have been active in the activities of MEHSOG. They were carried out in Tamale in the Northern Region, Accra in the Greater Accra Region, Bolgatanga in the Upper East, and Wa in the Upper West Region. The KIs were conducted on the Executive Secretary and selected leaders of the network of Self-Help Groups (SHGs) and representative district associations of the SHGs that make constitute the MEHSOG. Other key informants were staff of management of BasicNeeds Ghana, CPNs, psychiatrists and officials of district assemblies, including the directors of DSW and DCD, as well as Parliament (MPs) especially members of the select committee of Parliament on health.

Focus Group Discussion (FGD) was the other data collection tool that was used to build primary data of the study. FGD is a research tool in which a small group of participants gather, and through the group interactions, generate data on a specified topic or an issue determined by the researcher (Morgan, 1997, Wong, 2008). The objective of FGDs is to give the researcher in-depth understanding of participants' perspectives, opinions, experiences and attitudes on the issue under discussion (Wong, 2007). FGDs have been widely recognised as

a tool for exploring in-depth experiences, opinions and attitudes of groups of people irrespective of their level of literacy and numeracy, age, sex, and social class and disability. It also encourages active (Kitzinger 1995), p 299). FGDs were therefore most ideal for the service users and their families that were participating in the study. It encouraged deliberations in a reassuring atmosphere where participants did not feel inhibited to express their views. Just as KIs, the FGDs also provided good quality data within a short period and enabled the researcher tap into values of the existing sub-cultures, shared and common knowledge and areas of dissent or disagreements (Kitzinger, 1995). FGDs also helped in triangulation of information provided. FGDs will held with groups of members of SHGs, the GFD and similar networks, Community Psychiatric Nurses (CPNs) and relevant community based organisations connected with the activities of MEHSOG and its members SHGs and their representative district associations. Four regional level FGDs were conducted, one each in Tamale, Accra, Bolgatanga and Wa. This is consistent with the first core groups of service user groups that came together to establish the Mental Health Society of Ghana as a representative national mental health service users and carers association.

Interviews and discussion guides were developed detailing the key issues to be explored in depth during the KIs and FGDs. These were translated into the dominant local languages that are spoken in the various locations that the data was collected. The interviews were conducted in four regions of Ghana from where the first groups of SHGs came together to establish MEHSOG. These include the Greater Accra Region, Northern Region, Upper East Region and Upper West Region. These areas are coterminous with the operational areas of BasicNeeds Ghana, a mental health and development advocacy non-governmental organisation, that has been instrumental in the formation of national mental health service user and care-giver organisation.

These were interspersed with review of relevant documents related to activities of MEHSOG such as minutes of meetings and other reports, including newspaper publications on activities of the associations. Document review helped in building data for the study that may not had come out from use of the other methods. The review of the data was to answer how and why the documents were produced [Centre for Diseases Control (CDC), 2009; 1-2] and to serve for triangulation for other data that will be built as part of the study. Data was also collected through participant observation by researcher sitting into four meetings of MEHSOG at the national level. It made it possible for the researcher to immerse himself in the activities of the association without compromising the objectivity of the study.

3.7 Data Analysis

Analysis of the data collected was based on thematic analysis (Boyatzis, 1998; Braun and Clarke, 2006). Thematic analysis is a process of encoding qualitative information by building appropriate themes in such manner that the accuracy or sensitivity to understanding and making meaning out of people, event situations or organisations, it allows for rich data collected from KI and FGDs to be analysed in ways that give meaning for interpretation, drawing conclusions and making recommendations out of the qualitative data collected. Thematic analysis is appropriate for this study. It will made it possible for familiarisation of the data sets collected and development appropriate themes, categories and core concepts for interpretation and discussions.

Thematic analysis suited the qualitative case study research as this one. It made it possible for themes to be developed from the field data collected on the services and key policies that MEHSOG has influenced in Ghana. The KIs and FGDs were recorded for ease of reference and transcription. The recorded interviews and discussions were transcribed by hired resource person(s). Participant verification of the interpretation of the data collected

was useful and was done by on-going analysis of the data with the respondents as the data was being collected. The recorded interviews were transcribed by the use of hired resource persons. To ensure participant verification of the interpretation of the data there was on-going analysis of the data as it was being collected. It was part of ensuring rigour of the data for that matter maintaining the reliability and validity required in qualitative research such as this one study (Morse, Barrett, Mayan, Olson, and Spiers, 2002).

Causative answers and evidence to demonstrate the contribution of the MEHSOG to mental health policy and service development in Ghana were, among others, mainly included:

- Policy briefs produced on specific mental health issues
- Reports of representation meetings
- Mobilisation of individuals needing treatment services to access such services
- Media publications on advocacy and representation activities of MEHSOG.

Any three of these was an indication of their involvement in and influence of mental health policies and services in Ghana

3.8 Researcher's reflexive analysis

In qualitative research, data collection and analysis are not neutral as they reflect and imbue theoretical, epistemological and ontological assumptions, as well as conceptual perspectives and understanding of how knowledge and constructed (Mauthner and Doucet, 2003). The researcher took cognisance of this in this study and applied the principles of reflexive analysis in the collection and analysis of the data. Reflexivity is defined to entail "the researcher being aware of his effect on the process and outcomes of research ... it is impossible to remain 'outside' our subject matter; our presence, in whatever form, will have some kind of effect. Reflexive research takes account of this researcher involvement' (Thorpe & Holt 2008).

The researcher was conscious that his position as Executive Director of BasicNeeds-Ghana the organisation that has so actively supported the establishment of the national mental health service user and care-givers association does not influence data collection and analysis of this study. BasicNeeds' operations have been to have the active involvement of persons with mental illness or epilepsy in activities relating to their treatment and participation.

The principles of reflexive analysis were applied to assure quality and credibility of the data collected and the analysis made. The researcher ensured that a high level of selfawareness and self-consciousness was exhibited through out in the data collection and data analysis processes. This is consistent with experiences of Mauthner and Doucet (2003) in their perspectives on reflexivity in qualitative research. The researcher recognised his social location and maintained such neutrality in ways in which his emotional responses to the study participants did not influence the interpretations made of their responses to the questions of the study. In this regard, the transcripts of the key informants interviews and focus group discussions were done by persons different from those that collected the data. The transcripts were also read several times before coding of the data was done. Brown and Gillian, (as cited in Mauthner & Doucet, 2003,), refer to this process as the voice-centred method. This allows "the researcher to examine how and where some of her assumptions and views might affect her interpretation of the respondent's words, or how she later writes about the person (p. 419). Also that the social, emotional and intellectual assumptions of the researcher do not significantly affect the narrations of the respondents and interpretations made of them (Mauthner & Doucet, 2003).

3.9 Ethical consideration

Ethical issues in research concerned the safety of the subjects of the research (Shahan & Kelen, 2006). It pertains to doing well and avoiding harm (Orb, Eisenhauer, Wynaden,

2000) to research subjects. The guiding principles of ethics in research are as articulated by the Belmont Report which include, "respect for persons, beneficence, and justice" (Shahan & Kelen 2006; Orb, Eisenhauer, Wynaden, 2000). This research study took into consideration the theoretical and practical issues as discussed by Mauthner, Birch, Jessop, and Miller, (2002), which were in line with ethics in research which emphasise informed consent, confidentiality, anonymity, reliability and validity. This study involved human beings as subjects of the study however there was no risk to their safety.

Any ethical dilemma of obtaining informed consent from subjects with mental disorder, some of who may not be competent for consent was recognised as a potential challenge to overcome. This was overcome in the study by attention to working with SHGs of stabilised persons with mental illness or epilepsy and primary care-givers. Most of the members of the SHGs had gone through treatment and were stabilised of their conditions and state of mind to give independent consent and provide their views on the area of focus of the study.

It was the hope that the findings of this study would contribute to enhancing mental health service user and care-giver advocacy in mental health policy and service in Ghana. There could be implications for service users and carers that present a threat to their wellbeing by virtue of their participation in the study. These could range from community disapproval to threats from key stakeholders that MEHSOG deals with. This is however negligible and unlikely. The stigma associated with mental illness or epilepsy in Ghana could have the potential of leading to ridicule of respondent stabilised people with mental illness or epilepsy and their primary care-givers. This was assuaged by the extensive public awareness creation and education was going on through the operations of a number of non-governmental organisations and user groups as the ones to be involved in the study that has

significantly helped in changing attitudes. This helped reduce any compromises on the person and integrity of people with mental illness or epilepsy and their carers participating in the study.

Ethical approval for the study was obtained from the Research Ethics Committee of the Faculty of Medical Sciences of the New University of Lisbon in Lisbon, Portugal and the Ethical Review Committee of the Ghana Health Service in Accra. Permission was also obtained from the relevant institutions where participants were recruited to participate in the study. All participants of the study provided with written consent forms which completed and signed. The consent form was translated into the local language of the respondents to enable them fully understand and appropriately provide the consent required of them. Verbal consent was secured from respondents who could not read or write the English Language or provide signatures on the consent forms.

An assurance of the privacy and anonymity of the participants was guaranteed by providing generic statement of issues of views and opinions, and statement without mention of names and groups from which data was collected. Confidentiality of the data collected will be assured by safe-keeping of written questionnaire, voice recordings. Transcripts of recorded interviews and paper documents related to interview of respondents were packed into cases and locked away for safe-keeping. Protection of privacy of the respondents was also assured by the interviews being conducted in their usual settings to enable them have the confidence and not compromise their person or feel intimidated to speak out.

3.10 Dissemination of study

A Microsoft PowerPoint presentation summarising the study's aims and objectives and the research question it sought to answer was made to a cross-section of stakeholders, including the media. The presentation also covered the key findings, discussions of the

themes that emerged and recommendations were also made which gave insight to the study and its results and direction. This further publicised the activities of MEHSOG and its member mental health service users and primary care-givers.

CHAPTER FOUR

PRESENTATION OF FINDINGS

4.0 Introduction

This chapter presents findings of perspectives of mental health service users and care – givers in community mental health service provision and mental health policy in Ghana with the specific case to the Mental Health Society of Ghana (MEHSOG). The study participants were members of SHGs of mental health service users and their care-givers, Community Psychiatric Nurses (CPNs), and other community health workers, health authorities at the district, regional and national levels, as well as members of Parliament and other stakeholders.

4.1 Findings

The findings presented are categorised in to four parts, which cover the origins of the Mental Health Society of Ghana (MEHSOG) and its structure; major activities in mobilising people with mental illness or epilepsy to benefit from and influence provision of community mental health services and related policy; notable achievements in their self-advocacy efforts; challenges faced, and recommednations for future efforts. Each of these constitute a theme for discussions with sub-themes as may be appropriate.

4.1.1 MEHSOG, its origins and structure?

Understanding what study participants know of how MEHSOG came about was an attempt to gauge participants' appreciation of what MEHSOG stands for. By describing what was MEHSOG to them participants also conveyed their expectation of what such a structure should be for them. Service users and primary carer givers described MEHSOG as their

group that represents their needs and aspirations. By reference to their groups they mentioned that it was formed for them.

We formed the group to support our selves. It represents us and we know MEHSOG to be for our interest in Accra and everywhere [KI, service user]

Other respondents responded that MEHSOG is the amalgamation of the several community SHGs and their representative district associations that they belong to. It is the umbrella organisation of all the smaller community based groups of people with mental illness or epilepsy and care-givers.

What MEHSOG is exactly is that it is our mouth piece. It is the final place agreements as to how we proceed with concerns we have with the government, including the Ministers and Members of Parliament and health workers about services we should benefit are agreed. When we agree there it is final, [FGD, Primary carer]

Government officials and key stakeholders interviewed described MEHSOG the representative group of persons with mental illness or epilepsy and primary carer-givers of people with mental illness or epilepsy. They compared and described MEHSOG as one of the Disability People's Organisations (DPOs) that represents the interests of their members.

MEHSOG is one of the groups of persons with disability. It is the organisation that engages appropriate quarters for redress of concerns of persons with mental problems. It is not for just specific members but once the issue has to do with mental health and rights of persons with mental illness MEHSOG will takes it up [Director, Department of Social Welfare]

Generally, respondents viewed MEHSOG as the voice of mental health service users and primary carers. It is the identity and symbol of PWMIE. MEHSOG provides the structure within which mental health service users and their primary care-givers can articulate their views and be sure they will count. Respondents mentioned that the need to address the stigma, discrimination and absence of a recognised legally registered association to stand for the needs and rights of people with mental illness or epilepsy that brought about the establishment of MEHSOG. In this regard anyone seeking to associate with the association or

movement needed to subscribe to this important situation to address stigma and human rights abuses and support members to regain confidence and become active participants in community development processes.

MEHSOG represents the movement we need for people to take mental health and people with mental illness serious. It has enabled people with mental illness or epilepsy and their primary carers to build a good level of assertiveness to talk about their needs and rights. This assures discrimination and abuse is eliminated. Members also grow in confidence and rebuild their relationships. [KI, Service user and executive member of MEHSOG]

The structure of MEHSOG was described as a broad-based entity that drew its powers from the grassroots in the over 250 community SHGs and 72 district associations from which delegates come from to constitute the associations.

MEHSOG is the highest body of the national movement of mental health users and primary carers. However, we in the SHGs provide it the base from which it draws its powers and legitimacy. Therefore it serves us in our various SHGs [FGD, Primary carer and leader of SHG]

We have altogether some 17000 members from across the country. It is only through MEHSOG that we all speak one message and convey one idea of what we want to see change for us [FDG, Mental health service user]

MEHSOG is the apex body from which the several SHGs in the communities. The SHGs establish their district association and from the district association a delegate serves in the Annual General Meeting (AGM) of MEHSOG. It is at this level the agenda of MEHSOG, for that matter the user movement is determined based on which the secretariat executes on behalf of the association. The secretariat of MEHSOG has an Executive Secretary who is appointed at the AGM presided over by the President, who is elected by simple majority of the members of the AGM. Other members of the national executive committee are the treasurer and regional delegates. The secretariat recruits support staff to assist the Executive Secretary in the day-to-day running of the association (MEHSOG). MEHSOG has a five

member independent advisory body that provides technical support and oversees the sound governance of the association.

We have an elaborate structure as we seek to ensure anyone we engage with understand we are serious people who are clear with what we want achieve for our individual and collective good [FGD, Service user]

The study also looked at how one gained membership into MEHSOG. The responses as to how one qualified to be a member were that one must be living with a mental illness or epilepsy or is a primary care-giver of someone with mental illness or epilepsy.

To become a member of MEHSOG you must be duly diagnosed to have a mental illness or caring for someone with mental illness or epilepsy. This means you must be someone who is under treatment for your mental disorder [FGD, Primary care-giver, Tamale]

A key condition is that one must belong to a self-help group of people with mental illness or epilepsy, particularly those that were set up through the operations of BasicNeeds and the other organisations working with them. It is from the SHGs that MEHSOG emerged [KI, mental health service user]

With regards how they mobilised their members, study participants mentioned consultation meetings held with them that BasicNeeds-Ghana organised. Also the members formed their groups following from psychiatrist outreach clinics undertaken by specialist psychiatrist, mostly facilitated by BasicNeeds and the other NGOs in the communities and districts.

We became members of MEHSOG following a general meeting of delegates of district associations of SHGs to discuss the idea of having a national association, our self-help group was formed from the first meeting BasicNeeds held in our village with us to discuss what we thought we could do for ourselves with their support. Since then we have been working with the CPRI (Centre for People's Empowerment and Rights Initiatives) and the psychiatric nurses to mobilise more people with mental health problems. Our national delegate attends all the meetings of MEHSOG. [FGD, service user]

Following from these engagements, the SHGs so formed undertake membership drives by holding public awareness events such as visits to families known to have people

living with mental illness or epilepsy, and visits to churches and mosques to talk about mental health issues. Advantage was also taken of psychiatrist outreach clinics that attracted many people from neighbouring communities to talk to service users and primary care-givers coming for services about the SHGs existing or that could be formed. These attracted individuals and care-givers to join the groups or set up new ones for themselves.

I joined the group after some members of the SHGs in the village made regular visits to our house. That convinced my mother to join the groups and she made sure I came along with her to the meetings. It did not take long and I started going to the meetings all by myself. I sometime go ahead of my mother [KI, Service user]

As members of the SHGs we went to the churches and mosques to encourage people not to hide people with mental illness or epilepsy but that families should encourage them to come out and be part of our group [FGD, service user and leader of a SHG]

In appreciating what MEHSOG is to the respondents of the study and for, that matter, members of there was interest in getting views of respondents about the obligations of members of MEHSOG to their association. Obligations mentioned included not just financial contributions rather it was on the availability of the members to group meetings and activities of the SHGs and their national secretariat (MEHSOG).

Members' obligations to the association are to ensure they meet their financial commitments. However, it is their presence at all meetings and activities of the individual groups and MEHOSG that is most important. We need the numbers to remain relevant; else we will continue to be discriminated against. There are many who are yet to come forward and we hope the do soon [FGD, Service user and president of a SHG]

Service users and primary caregivers that participated in the study mentioned that a key requirement to being part of SHGs and for that matter MEHSOG was that one needed to have been professionally diagnosed or is one recognised in the community as main care-giver of a person with mental illness or epilepsy.

We want people who are truly having the conditions we have and that imposters don't take advantage of us because they now see some people coming to help us. So we must be convinced that you have been diagnosed with a mental illness or epilepsy or you must be recognised in the family and community to have a someone with mental illness or epilepsy that you are the main person caring for such a person and have brought such a person forward for treatment [FGD, mental health service user]

4.1.2 The mental health legislation/ policy context

The mental health legislation and policy context being explored was to establish study participants' appreciation of the metal health situation that prevailed before the emergence of MEHSOG. It also was to enable them understand the issues in mental health that service users and primary carers encountered and worked on to address through their groups and how they were addressed before MEHSOG came into being.

Responses of participants indicated the mental health environment was one that was neglected and where people with mental illness or epilepsy and their families hardly featured. Members of MEHSOG seemed well aware that they were hardly any subject of attention as an important stakeholder, individually and as groups, in mental health service and policy direction.

The situation was that we hardly heard of mental health issues or discussions about our situation, how people with mental challenges fare and how and when the can be supported to have treatment for the illness and a means to a livelihood [FGD, Mental health service user]

The mental situation was associated with sensational issues about acts of 'mad people' in the newspapers or radio. If there was any other discussion at all it was about the psychiatrists or medical person and their practices [KI, primary carer]

There was a general sense by study participants that the mental health context in Ghana was one that operated within out-of-date law and policy, with no programme in place to focus support that will bring about care system in Ghana that is community oriented and effectively

responds to the needs and rights of persons with mental illness or epilepsy and their primary carers and families as enumerated below:

The mental health situation is Ghana is one in which the psychiatric hospitals is what is of interest with poor developed community services [KI, mental health service user].

We learnt that Ghana's mental health law is an old one that still subscribes to separately treating people with mental illness from the psychiatric hospitals. Mental health is not well included in general health care services in the hospitals and clinics in the districts which has not allowed community mental health services to [KI, Primary carer]

Involvement of people with mental illness or epilepsy and their carers was not Existing [FGD, Primary carer]

Mental health is hardly seen as apriority in most government departments so I will say the context is one of inadequate regard to mental health and the impact of the illness or pour lives [KI, District Coordinating Director]

Beyond the mental health policy and service environment, there general legislation and policy context was found to be favourable of activities of civil society organisations, including such citizen groups as MEHSOG. The presence of vibrant civil society entities in the Ghana provided fertile grounds for the presence and activities of MEHSOG. Respondents mentioned the constitution of Ghana and related laws as having made it possible for them to operate their association.

The constitution of Ghana allows for freedom of association. There is also recognition that those disadvantaged should be supported to also come up. There are organisations that are also ready to support us also become known and support one another [KI, Primary carer]

We have come to appreciate that civil society organisations can do a lot to help the work of Parliament. The engagement of this group has been an eye opener for us and we value how much they have made mental health an issue for Parliament to sit up and address. We represent our people and we must be seen to supporting the vulnerable ones more [KI, Member of Parliament of Ghana]

Responses of participants indicated the constitution and the UN conventions and treaties were attempts to development of participation processes that could enhance their involvement in discourse with health and development policy authorities and the general public.

Two levels of engagement were established. One was trying to give them legitimacy to the groups and their national association (MEHSOG) and another, which was meant to sensitise and draw attention to existing inadequacies that is not make it possible for mental health service users and their carers to benefit from state public social protection programmes, including absence of an up-to-date community-based mental health legislation. On the front of establishing their legitimacy, SHGs and their members targeted local authorities, officials of decentralised government MDAs and frontline staff of MMDAs. Excerpt of an interview of a service user in relation to this issue

We undertook various public activities such as durbars where we discussed mental health issues. The CPNs helped and NGOs helped in the durbars. On our own, we requested pastors and imams to visit their churches and mosques to speak about mental illness or epilepsy, and our group and what we do. We used ourselves as examples of how we have successfully overcome our illness and begin be ourselves again. With confidence we speak about of our situation and do get people not just to listen but become active service users themselves [FGD, Mental health service user]

4.1.3 Role of MEHSOG and the SHGs in community mental health service provision

The role of MEHSOG in the community mental health services was very much an important measure of the contribution of a user movement of its kind in influencing service provision. Increasing and enhancing access to basic mental health care services is a key measure to how members feel they benefit by being part of a service user association. MEHSOG actively supported provision of services in deprived and hard-to-reach locations of

Ghana. The SHGs mobilised their member to attend specialist psychiatrist outreach clinics by ensuring they relayed messages of the coming of the psychiatrist to their members and the communities. MEHSOG specifically worked with BasicNeeds to organise outreach clinics in four polyclinics within the Accra metropolitan area.

When information reach us that the psychiatrist will be coming around to provide treatment we relay the message in our SHGs and send the same message to the central mosques and notable churches for announcements to be made. Through that people from the neighbouring communities and distant parts attend to receive services [FGD, mental health service user].

Our educational campaigns have helped in making people know that mental illness does not need to be treated with just prayers but also with medicines and they are available in the hospitals in the psychiatric units [KI, Primary carer and executive member of MEHSOG]

Respondents also mentioned supportive activities within the SHGs which help to remedy and provide the emotional and psychological stability to the service users and primary carers. Through the SHGs service users and care givers enhance their capacity to self-management and confidence building. Respondents mentioned that they valued the learning they had about the illness conditions. It made them understand themselves and their conditions better

We were made to understand that even in illness we are not useless. We learnt to accept our condition and to learn to take care of ourselves, respecting the very gifts God gave us [FGD, Service user]

Shortage of medicines has affected effective provision of mental treatment services in Ghana. The SHGs have been vocal in calling for the increased supply and availability at the Community Psychiatric Units (CPUs).

For example the Wuni-zuaya SHGs in Walewale successfully lobbied the West Mamprusi District Assembly to provide then four thousand Ghana Cedis from the District Assembly Disability Common Fund (DADCF) which they channelled to the CPU at the

Walewale district hospital to stock medicines to service people with mental health needs. This was due to efforts of the SHG and the leadership of the district association of the SHGs.

Respondents also highlighted that the presence of an organised mental health service user group helped change attitudes of the service providers towards persons with mental illness or epilepsy that came for services.

Through the SHGs service users were more organised during the specialist outreaches. This level of orderliness earned service users and care-givers more respect. We are now better informed about our illnesses and engage in better discussions with the psychiatrists and CPNs about our illnesses [FGD, service user]

4.1.4 Supporting livelihoods and means to income generation

Respondents identified and extensively spoke about the value of being productive and able to earn an income as an important aspect that the users association has been able to bring about. Right from the neighbourhood SHGs through to the national secretariat of MEHSOG there has been sustained advocacy and practical support to enabling service users and primary care givers to [re-] enter the world of work to productive again and to earn an income. Being involved in productive activities and an ability to earn was found to be significantly contributed to reducing stigma and discrimination in the family and community and increasing acceptance and respect. Service users themselves and their primary care-givers grow in confidence and become more assertive in claiming their rights.

We don't only discuss our illness and how to ensure all who need mental health services have them. We also encourage and support our members to engage in productive activities. Many people have re-established their businesses many others who had no skill have taken up apprenticeships to acquire technical and vocational skills that can enable them establish enterprises to earn income from such ventures [FGD, service user]

MEHSOG has been instrumental in getting various SHGs to successfully access cash grants from under the disability common fund of district assemblies. This helped them secure

financial grants to which they have shared among themselves for use to establish and/ or expand existing enterprises.

The Accra Metropolitan Assembly provided us an amount of eight thousand Ghana Cedis which we used to give out to individual member to start their ventures. It helped member to start petty trading, others used to pay fees for apprenticeship whilst others started a piggery and other craft [FGD, primary care-giver]

The mental health group is one of the disability groups that benefited from the grant. The committee found their application to focused on helping their members become more useful to themselves so it was easy to give them the grant to for them to engage in income earning ventures [KI, district director of social welfare]

Respondents also mentioned that MEHSOG had also been active in advocacy for formal employment and worker rights for people living with mental illness with mental illness and their primary care-givers.

4.1.5 Contributing to mental health law of Ghana

MEHSOG was a key and vocal stakeholder in the call and campaign for a new and up-to-date mental health law for Ghana. Responses of study participants indicated that MEHSOG was a key and vocal stakeholder in the call and campaign for a new and up-to-date mental health law for Ghana. Responses recounted a number of activities MEHSOG led as part of part of advocating for a new and up-to-date mental health Law for Ghana. Study participants mentioned that MEHSOG undertook region-wide exercise to educate members of the SHGs about what the law contained.

MEHSOG undertook to educate us about the key provisions of the mental health Bill and made us understand that the new mental health Bill will be in our favour. They organised workshops and took us through what the Mental Health Bill contains. Mental health will become community based and more widely available to all who need it and service users will be more involved in decision-making [FGD, primary care-giver]

Mental health service users and primary care-givers who participated in the study found the education on the Mental Health Bill as another form of empowerment. It brought about a shared sense of purpose among the members of the SHGs building in them a sense of mission to see to the passage of the Mental Health Bill.

From the orientation we got about the provisions of the Mental Health Bill, we became better sensitised. We also saw is a call on us to contribute our quota to bring about a new Law so that we can be better recognised [KI, mental health service user]

Respondents mentioned engagements they had with legislators and the Minister of Health to petition for speedy passage of the Mental Health Bill into Law.

We mobilised our leaders and key representatives to meet with the members of the Health Committee of Parliament. I was one of those that met the committee. We well received by the committee and I think for the first time, they realised that we are not all mad with no sense. I think this convinced them to do more for us by ensuring the Bill became law. The media also widely covered these meetings and put pressure on the government to act. [FGD, mental health service user]

Respondents also mentioned other activities which included route marches and presentation of petitions to the Minister of Health and the leadership of the health committee of Parliament. There were also extensive media based interviews and panel discussions usually provided by the media for advocate for the mental health Law to campaign for the Mental Health Bill becoming Law.

Alongside BasicNeeds-Ghana and the other psychiatrists that were actively campaigning for the Mental Health Law we held many television and radio discussions, virtually calling for the quick passage of the Mental Health Bill into Law so that mental health can change for the better in Ghana. [KI, psychiatrist]

MEHSOG members were always represented and brought the perspectives of users and care-givers to bear on the discussions. This was key and will have been missing without MEHSOG [KI, Director of Social Welfare]

Activities of MEHSOG also helped to significantly change attitudes about mental disorders and people with mental illness or epilepsy as users openly discussed their

experiences and having successfully come out of the illness to be active advocates for improved policies and services that are inclusive of the needs and rights of persons with mental illness or epilepsy.

Hearing us speak out our experiences with mental illness the places we were taken to and the bad treatment we were subjected to helped to make people appreciate the need for greater support to persons with mental illness. I think the media also changed their perceptions and attitudes. They had several interviews with me and some of our members and produced feature stories and documentaries which they played in their networks. Our willingness to share our experiences helped in changing attitudes and practices [FGD, mental health service user]

4.1.6 Challenges

MEHSOG as a mental health user and care-givers association obviously faced challenges in their quest to make mental health services more accessible and public policies more inclusive of the needs and rights of persons with mental illness or epilepsy. Study respondents mentioned key challenges to include low literacy levels of most of their members, inadequate funding and the engrained stigma associated with mental illness and for that matter the people living with such conditions, including care-givers of people with mental illness or epilepsy.

Most of our members have not been to school and cannot speak English Language which is an important means of communication in Ghana if your advocacy efforts are to make sense to the wider public. The few numbers of people who could express themselves were few and did not make the majority actively participate as they could at the national level [FGD, Mental health service user]

Funding constraints affected how far MEHSOG could go in reaching out to it member groups across the country and maintained a sustained advocacy agenda. Adequate funding was highlighted as was key challenge that limited how far the user association could go in Ghana.

Except for the funding that was provided by BasicNeeds which came through Comic Relief and DFID, MEHSOG did not have any funding of its own to support sustained engagements with duty bearers. Influencing and advocacy activities are expensive and to remain relevant and true to our aim to ensure public services and policies benefit the majority of people with mental illness or epilepsy we need to secure good levels of funding to prosecute our agenda [KI, Executive secretary, MEHSOG]

Despite the extensive public education carried out through the activities of MEHSOG and other mental health organisations, stigma and general ignorance of mental disorders remain very pronounced and affect the number of officials that MEHSOG and its members could engage.

We had difficulties even meeting our DCEs for them to give us a hearing and support our cause to have better services and policies that will enable us satisfy our basic needs and exercise our basic rights. There are still people who despite being big men with education who don't still support mental health issues and people with mental illness and their carers [FDG, primary care-giver and secretary to a SHG]

4.1.7 Recommendations

Study respondents were encouraged to provide recommendations for making MEHSOG and for that matter the user movement in Ghana better achieve its aims and objectives.

We have to mobilise more members and be serious in our SHGs so that visibility of people with mental illness or epilepsy can be sustained [FGD, primary care-giver]

There should be a programme of education continuously for us. As more people get well from their conditions they now need to be trained to be able to engage in some income generation activities. Also, the education I am talking of here is for us to be better informed and able to know how to engage with government authorities in order to hold them to account for their promises and duties [KI, mental health service user]

This is an important association and I commend them for their efforts. My suggestion is that it will do them a lot of good if there link up with like-minded organisations in Ghana and beyond so that they could benefit from funding and exposure [KI, District Director, Department of Social Welfare]

4.1.8 Conclusion

This study was to understand and document the contribution of the service users and care-givers in mental health services and policy advocacy with specific reference to the Mental Health Society of Ghana. The study documented key informants perspectives on the key activities related to mental health service provision and policy advocacy of MEHSOG based on interviews and focused group discussions that.

CHAPTER FIVE

DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction

This study sought to document the perspectives of health users and care-givers associations in community mental health service provision etc. and their role and contribution as it was perceived by a number of key informants including users themselves in Ghana with specific reference to the Mental Health Society of Ghana (MEHSOG). This was part of attempts to articulating the relevance and particular contributions of service users and care-givers in promoting mental health treatment services for the populations and in bringing about inclusive policies that enable people with mental illness or epilepsy to claim their rights.

5.1 Discussions

Findings of the study traced the origins of MEHSOG and its structure and current membership of the association. The findings also documented the mental health legislation and policy environment that were existing prior to the emergence of MEHSOG. This was meant to give a picture of what was pertaining in the mental health front in the absence of an organised group of mental health service users and care-givers. The remaining sections of the findings covered the specific contribution(s) of MEHSOG, and by extension its associated SHGs in community mental health service provision, including support to livelihoods of the members within their respective SHGs, as well as the contribution of MEHSOG to the new mental health law (Act 846, 2012) of Ghana. Challenges encountered were also documented together with recommendations respondents made that could make the service user movement more relevant in mental health treatment service provision and policy development.

Overall, three themes emerged for discussions in this study. They include the organisation of MEHSOG as a structure and voice of people with mental illness or epilepsy in Ghana, leadership and participation of mental health service users and care-givers in the country and the specific contributions made in mental health service provisions and in development of policies. The potential of MEHSOG in in-country and wider collaborations and advocacy for the needs and rights of poor and vulnerable people with mental illness or epilepsy also emerged for discussion.

5.2 MEHSOG as a structure and voice of people with mental illness or epilepsy and their care-givers

Overall the findings established that belonging to a group or an organised structure of citizens is an important process to regaining and dignity, building confidence and exercising a sense of citizenship. Having a sense of social status and personal identity is a sure means to being empowered. This was captured by Kleintjes, Lund and Swartz (2013) in their study of nine user-led associations in Africa which included MEHSOG.

Self-advocacy required mobilising members and numbers in order to build the needed identity and legitimacy to represent the needs and interests of the members – mental health service users and primary care-givers. MEHSOG did this by ensuring there was a broad-based representation across the country. Members were already well prepared from the operations of BasicNeeds and therefore had experience of organising themselves. This made it possible for effective mobilisation and coming into being MEHSOG. It made it possible for an interim to be established to go through the process of formally registering for a national users and care-givers association.

Earlier studies of Crossley and Crossley (2001) and Kleintjes, Lund and Swartz (2013) traced the growth of voice of mental health service users and their current place in

ongoing public health and social services discourses. Crossley and Crossley (2001) study traced and compared how the voice of service users was articulated in the 1950s and the 1990s and concluded that the voice of mental health service users was historically and socially constructed. They note that the voice of mental health service users in the 1950s was more of a plea for sympathy and understanding, while that of the 1990s was more of assertive and confrontational by the service users themselves with little pleadings for justification or for someone to plead on their behalf or vouch for them. In the case of MEHSOG, it is combination of the two epochs. In Ghana there is still a great need to plead for the case of people with mental illness of epilepsy as was the case of the 1950s (Crossley & Crossley, 2001, Funk et al, 2005), but there is also a very vibrant, articulate self-modelled core of service users who based on their personal experiences regularly speak for themselves and the many service users and primary care-givers. MEHSOGs has been successful in being the voice of service users due to the many credible and well-meaning people who speak for and support their course but also by the core group articulate, confident and uncompromising survivors and primary care-givers (Funk, 2005; Yaro & de Menil, 2011).

In this whole process and level of organisation, leadership was found to be key in building the required critical mass to influence services and policies for people with mental illness or epilepsy. MEHSOG took leadership of the group serious right from its origins. It did this by having an experienced executive secretary to see the day-to-day running of the secretariat of the associations. It also allowed for sustained support and grooming by NGOs in the mental health sector, particularly BasicNeeds, which did not only provide funding but technical and moral support to the SHGs and the members and leaders. Psychiatrists and legislators in Ghana also support and spoke for them and their component SHGs. This was effective not just in building the voice but also in giving notice to relevant government

agencies concerned to accord MEHSOG visibility to engage. Through these, MEHSOG successfully emerged as a credible users and care-givers' organisation representing the needs and rights of its members and all persons living with mental illness or epilepsy and their primary care-givers. MEHSOG has therefore come a long way. Starting with just community-based SHGs the association evolved right from the grassroots building a groundswell of key service users articulate and assertive and who understood the need to ensure they actively participated in decision-making at family, community and societal levels. Kleintjes, Lund & Swartz effectively articulate this in the of mental health user movements in Africa, which include MEHSOG. It is similarly consistent with the work of Crossley and Crossley (20001) that traced and compared the growth of the mental health user movement of the 1950s and the 1990s. The involvement of government in advocacy for mental health is also advocated by Funk et al (2005).

5.3 Building mental health service user movement to improve participation and inclusion

The efforts of MEHSOG to improve participation and inclusion were hinged on a sustained awareness creation to challenge and reduce the stigma associated with mental illness or epilepsy and their primary care-givers. Making use of the articulate stabilised members there was a sustained public education drive carried out to drum home the need for more respect and acceptance of people with mental illness or epilepsy and their primary givers. The media was an important medium though which MEHSOG prosecuted its awareness creation agenda. It ensured participation by ensuring as many of its members as possible were involved in the public activities they.

MEHSOG actively involved itself and its members in Legal frameworks that provided support for establishment and operations of MESHOG were guaranteed in the fourth

republican constitution of Ghana and specific legislations such as the Disability Act (715, 2006), as well as several conventions and treatise of the United Nations that Ghana has signed up to, particularly, the Convention on Rights of Persons with Disability (CRPD) and the Convention on Civil and Political Rights and the Africa Charter on Human and People's Rights.

MEHSOG drew parallels with the physical disability people's organisations and by building their own associations assured a sense of representation of the issues within the disability fraternity in Ghana. This should be recognised as key to the relevance and existence of the association. It had the unique identity of being 'the user and care-giver based group' that represented the needs and rights of mentally ill people and people with epilepsy and their primary carer-givers.

5.4 Organising to advocate for improved treatment services and a means to livelihood

In organising to self-advocate, MEHSOG has been able to mobilise a critical mass of service users and primary care-givers to understand and support the demand for and realisation of their needs and rights. The involvement of MEHSOG in mobilising members to benefit from services, engage in livelihoods activities, and take positions on public policies and programmes meant to address health and poverty of populations provided mental health service users the opportunity for the members to appreciate their persons and influence they have to leverage services and policies in their favour. Individually, it would have been impossible for mental health service users or primary care-givers to have the required space and muster the needed confidence to engage and ensure services reach poor and disadvantaged communities. Inadequate access to services and resources even limited the

extent mental health service users could benefit from those services and be activities participants in policy advocacy.

There was therefore a focus to regularly mobilising members and encouraging them to go hospitals for treatment. The SHGs meetings served as peer-support sessions where members provided the needed emotional support to members who were in difficulty. Discussions around the side-effects of medicines service users are on served as important education to people who hardly benefitted from quality time with the psychiatrist/ of CPN. Members therefore had good for within which to gain adequate education on living with their disorders (Kleintjes, Lund & Swartz, 2013).

Yet another area that MEHSOG played a significant role for members related was the opportunity for members to engage in livelihoods activities. This was particularly made possible by the community SHGs that in were the communities across the districts and regions. A means to re-enter the world of work and become productive, including earning an income, was found to be one of the key practical demonstrations that gave reason for service users to belong to groups and for that matter be part of MEHSOG. Members particularly found the opportunity to access cash grants and financial credit from NGOs through MEHSOG a remarkable demonstration of organising into representative entities. MEHSOG provide the added structure within which social collateral can be built and to serve as guarantee for financial and equipment support to members. This is has been well documented by BasicNeeds (2009, 2013, 2014).

5.5 Influencing policies for inclusion

MEHSOG's efforts at bringing about inclusive policies are seen mainly in the advocacy for the new Mental Health Law of Ghana (Act 845), the free registration of poor

mentally ill people and people with epilepsy in the National Health Insurance Scheme (NHIS) and the District Assembly Disability Common Fund (DADCF) for PWDs and their DPOs.

On the Mental Health Law MEHSOG actively ensured the draft bill explicitly recognised and provided for the inclusion of service users in planning services and development by providing for representation of service users in the Board of the Mental Health Authority and in committees. Respondents had the conviction that even though the without them there could have been provisions that factor inclusion of mental health services users in the Law the presence of MEHSOG at the time the draft Mental Health Bill was being discussed provided justification for the recognition of attention to their needs ensuring the Bill did not become overly medical in emphasis. The involvement of MEHSOG in the calls for the passage of the mental health Bill into law also significantly contributed in add urgency to the need for the law to be promulgated to promote and protect the health needs and rights of mental health service users. This was perhaps the highest point of involvement of service users in mental health legislations and the presence of MEHSOG at that time was not only timely but necessary.

Mental health service users and care-givers took up the need to have a full grasp of what provisions in the mental health Bill stood for them and to raise issues with areas that were not adequate catering for their peculiar needs and rights. The advocacy for the mental health law helped to rally members of MEHSOG to appreciate collective advocacy.

Alongside the advocacy for the mental health Bill to become law was the submission of memoranda as part of amending the National Health Insurance Act (650, 2003) of Ghana, to include people with mental illness or epilepsy alongside pregnant women to receive treatment services free of cost.

5.6 Potential of MEHSOG for wider service user advocacy

The potential of MEHSOG in wider advocacy for improved mental health care services and policies is seen mainly in its place in the Africa user movement. In-country MEHSOG is a member of the Ghana Federation of the Disabled (GFD) where it serves in the steering committee and is also a member of the Board of the national disability council of Ghana. Similarly, as a member of PANUSP and such global patient movement as the International Alliance of Patient Organisations (IAPO), MEHOSG has established a strong foothold as an influential member within West Africa and the Pan-African users' movement. It fulfils calls already made by earlier researchers in this regard (Funk, 2015; Kleintjes, Lund & Swartz, 2013; and Battman & Johnson, 2009).

5.7 Challenges

Key challenge of MEHSOG is to be able to maintain the needed influence to go beyond expressing voice to actual representation where service users are part of the entire process of planning, implementation, monitoring and evaluation of mental health services and policies. The frustrations the service users and care-givers express have been the difficulty of involving users effectively in planning processes. Not even the newly constituted Mental Health Authority of Ghana has effectively ensured this for which a lot more effort is required to bring this about. This clearly because it will still take some time for the doubts and misconceptions about mentally ill people and their capacity to determine for themselves their needs and rights to take place. Wharme, Langdridge, & Motzkau (2012) equally raise this in their study stating that user empowerment is more controlling than is intended to empower.

It remains unclear how the MEHSOG ensured accountabilities for any excesses that might have been committed in service provision. This was probably so because no such cases were documented to be able to gauge how service users and care-givers would have reacted.

It however remains clear that needs to do more to be able to have the muscle to flex on service provision.

5.8 Recommendations

The shift in acceptance and support for people with mental illness or epilepsy and their care-givers through the establishment of MEHSOG, despite the obvious challenges, provide opportunity to continuously building on their involvement and representation in decision-making processes. Following from this study, a number of opportunities and measures could be pursued to maximise the advocacy role in mental health services and policies.

First service users should continue to organise themselves through their community SHGs to benefit from peer support and shared learning. Through this they can continuously use their numbers to influence their families and communities, for that matter wider society.

Secondly, MEHSIG should take advantage to build alliances and get involved in other citizen movements and network and coalitions. This has been amply demonstrated in the GFD, PANUSP and the IAPO. However, MEHSOG and its respective structures should extend their involvement and participation in other civil society coalitions that focus of good governance, and gender and women's rights in order to secure and enjoy wider support and presence.

The support and influence of the media cannot be over-emphasised. The support and reportage of the media on the need for inclusions and participation of mental health service users and care-givers in civic activities and reduce the sensational and negative stories about mentally ill people and their disorders. These will surely go a long way to reducing stigma and promoting.

Finally, government health and development authorities from the district assemblies and at national level could play a significant role in sensitising other government public policy makers and the general public to take steps to increase information of the needs and rights of persons with mental illness or epilepsy and their primary care-givers. Emphasis on public policies to address their needs and rights as vulnerable citizens will go a long way to reduce marginalisation and exclusions and to increase acceptance and support.

There is no doubt that further research is needed into the contribution and influence of mental health service users and care-giver movements in Ghana, Africa as whole and globally. This study should serve as motivation to this researcher and others to take such subject up a notch higher to give the needed recognition and support to mental health care service provision and policy development. This will go a long way to bring about scale up of community mental health service services integrated into general health care and inclusive policies for a healthier population.

5.9 Conclusion

There is no doubt that the presence of MEHSOG has opened a new chapter for service user advocacy and support to individuals living with mental illness or caring for people with mental illness or epilepsy. It attempts to demonstrate the gradual move of service users to just expressing voice to actually determining the course affairs of mental health treatment services and related policies to increasing decision-making. Active involvement in treatment service provision, a means to a livelihoods and support to legislative processes has put MEHSOG in a good stead to remain a credible citizen group to mobilise service users to benefit from services, including livelihoods ventures, and in promote pro-poor public services inclusive of needs and rights of people with mental illness or epilepsy and their primary care-givers.

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APPENDICES

KEY INFORMANTS INTERVIEW

Project Title: 'Contribution of mental health service users to mental health services and policy in Ghana – The case of Mental Health Society of Ghana (MEHSOG)'

Interview guide for key informant interviews with mental health service users and caregiver members of the Mental Health Society of Ghana (MEHSOG).

Introduction:

Interviewer introduces him/herself and the study, and guides the interviewee through the informed consent form.

Interviewee introduces him/herself and their membership and position/role in MEHSOG.

Part 1: MEHSOG and what it is?

- 1.1 Let's talk about the Mental Health Society of Ghana (MEHSOG), what is it?
- 1.2 How does one gain membership to MEHSOG
- 1.3 Are there obligations to being a member of MEHSOG and what are they?
- 1.4 How does MEHSOG represent the needs and rights of its members?

Part 2: The mental health legislation/policy context

- 2.1 What has been the role of MEHSOG and the individual SHGs in community mental health service provision?
- 2.2 Current discourse on mental health in Ghana is about the mental health Act, what do you know about?
- 2.3 Give me your understanding of such social protection schemes such as National Health Insurance (NHIS), Livelihoods Empowerment Against Poverty (LEAP)
- 2.4 Have you benefited from either one of these and how did that come about?

2.5 Explain to me how satisfied you have been with regards the role and contribution of MEHSOG to the mental health Act

Part 3: Recommendation on the way forward

- 3.1 From your point of view how could MEHSOG position itself and operate in such ways as to increase its influence on national mental health policy/legislation and community service?
- 3.2 How could government, donors and other relevant institutions support the advocacy and influencing efforts of MEHSOG?
- 3.3 Please, feel free to give any final words you may have.

Thank you very much for your commitment to improvement of mental health in Ghana

KEY INFORMANTS INTERVIEW

Project Title: 'Contribution of mental health service users to mental health services and policy in Ghana – The case of Mental Health Society of Ghana (MEHSOG)'

Interview guide for key informant interviews with government officials and key stakeholders in [mental] health and development in Ghana.

Introduction:

Interviewer introduces him/herself and the study, and guides the interviewee through the informed consent form.

Interviewee introduces him/herself and their membership and position/role in MEHSOG.

Part 1: MEHSOG and what it is?

- 1.1 Let's talk about the Mental Health Society of Ghana (MEHSOG), do you know about this group and what is it?
- 1.2 How does MEHSOG represent the needs and rights of its members?
- 1.3 Name and describe any organised group of mental health service users and care-giver groups operating in Ghana that you know of

Part 2: The mental health legislation/policy context

- 2.1 Give a concise briefing about community mental health service provision in Ghana?
- 2.2 Current discourse on mental health in Ghana is about the mental health Act, what do you know about?
- 2.3 Give me your understanding of such social protection schemes such as National Health Insurance (NHIS), Livelihoods Empowerment Against Poverty (LEAP)
- 2.4 In your opinion how have these benefited poor and disadvantaged people, especially, poor people with mental illness or epilepsy and their primary care-givers?
- 2.5 Explain to me how satisfied you have been with regards the role and contribution of MEHSOG to the mental health Act

Part 3: Recommendation on the way forward

- 3.1 From your point of view how could MEHSOG position itself and operate in such ways as to increase its influence on national mental health policy/legislation and community service?
- 3.2 How could government, donors and other relevant institutions support the advocacy and influencing efforts of MEHSOG?
- 3.3 Please, feel free to give any final words you may have.

Thank you very much for your time to participate in this interview

PARTICIPANT INFORMATION AND CONSENT FOIRM

TITLE OF THE RESEARCH PROJECT:

Contribution of mental health service users to mental health services and policy in Ghana – The case of Mental Health Society of Ghana (MEHSOG)

PRINCIPAL INVESTIGATOR: Mr Peter Badimak Yaro

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You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee at the Faculty of Medical Sciences, New University of Lisbon, Portugal and the Ghana Health Service Ethical review Committee, in Accra, Ghana and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

You are being invited to take part in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear of if you need more information.

This study aims to assess contribution of Contribution of mental health service users to mental health services and policy in Ghana, using the case of Mental Health Society of Ghana (MEHSOG).

The study aims to:

- describe the role and level of influence of MEHSOG to Ghana's mental health legislation and in organisation of community mental health services" from the perspectives of members of MEHSOG and other key stakeholders in [mental] health and development".; and
- identify opportunities greater and challenges that may limit effective participation and influence of service users in mental health policy and service development

The study will be conducted in northern Ghana, which covers the three northern regions, namely Northern Region, Upper East Region, and Upper West Region, as well as in Accra in the Greater Accra Region. A total of 25 participants will be recruited for the study.

You will participate in an interview where you will be asked a number of questions, with follow-up questions to clarify your responses. Your expected time commitment for this study is one hour.

Why have you been invited to participate?

This study is collecting in-depth views, opinions, and perspectives on contribution of mental health service users to mental health services and policy in Ghana using the Mental Health Society of Ghana (MEHSOG) as a case-study.

You have been identified as a key stakeholder involved in mental healthcare policy decision-making and/or service provision in Ghana or beneficiary of mental health policies and services.

What will your responsibilities be?

You are expected to spend an hour of your time responding to a series of questions that you will be asked by an interviewer. You are to answer them as clearly as possible providing as much information as you can. You may be asked follow-up questions to clarify any issues that are not clear to the interviewer.

Will you benefit from taking part in this research?

There will be no direct benefit to you for your participation in this study. However, the information obtained from this study will contribute to improving access to the provision of comprehensive mental health care services for people with mental illnesses and epilepsy in Ghana and globally.

Are there in risks involved in your taking part in this research?

The risks associated with study participation are minimal. These risks are similar to those you experience when disclosing work-related information to others. You may decline to answer any or all questions and you may terminate your involvement at any time if you choose.

If you do not agree to take part, what alternatives do you have?

If you do not agree to take part in this study, you are free to say so and you will not be asked any further questions, even if you would have started with the interview.

Who will have access to your medical records?

This study will not involve use of your medical records. Your responses from the interview will be kept confidential and protected. Your information is going to be used in a thesis and for the purposes of this research project your responses and comments will remain confidential. Every effort will be made by the researcher to preserve your confidentiality including the following:

- Assigning code names/numbers for participants that will be used on all researcher notes and documents.
- Notes, interview transcriptions, and transcribed notes and any other identifying participant information will be kept in a locked file cabinet in the personal possession of the researcher. When no longer necessary for research, all materials will be destroyed,

The researcher will review the collected data. Information from this research will be used solely for the purpose of this study and any publications that may result from this study. All other participants involved in this study will not be identified and their anonymity will be maintained.

Each participant has the right to obtain a transcribed copy of their interview. Participants should tell the researcher if a copy of the interview is desired.

Will you be paid to take part in this study and are there any costs involved?

You will not be paid to take part in the study. However, any costs related to travel and transport, and meals to enable you take part in the study will be covered for each visit you have to make. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

- ➤ You can contact Yaro, Badimak Peter at telephone numbers +233(0)24 457 27 33 if you have any further queries or encounter any problems.
- ➤ You can contact the Faculty of Medical Science of the New University of Lisbon at +21 880 3000 if you have any concerns or complaints that have not been adequately addressed by your Principal Investigator.
- ➤ You can also contact the Administrator of the Ethical Review Committee of the Research and Development Division of the Ghana Health Service +233 (0)302 681109/ (0)302679323 if you have any concerns or complaints that have not been adequately addressed by the Principal Investigator.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (place)	on (<i>date</i>)
Signature/Thumbprint of participant	Signature of witness
Declaration by investigator	
I Yaro, Badimak Peter declare that:	
discussed above	
Signed at (place)	on (<i>date</i>)
Signature of investigator	Signature of witness
Declaration by interpreter	
 using the language medium of a Ghanaia We encouraged him/her to ask questions I conveyed a factually correct version of 	k Peter to explain the information in this an Language. and took adequate time to answer them. what was related to me. understands the content of this informed
Signed at (place)	on (<i>date</i>)
Signature of interpreter	Signature of witness

ETHICAL REVIEW APPROVAL LETTERS

GHANA HEALTH SERVICE ETHICAL REVIEW COMMITTEE

In case of reply the number and date of this Letter should be quoted.

My Ref. :GHS-ERC: 3 Your Ref. No.



Research & Development Division Ghana Health Service P. O. Box MB 190 Accra

Tel: +233-302-681109 Fax + 233-302-685424 Email: Hannah. Frimpong@ghsma.

28th March, 2014

Yaro Badimak Peter Basic Needs-Ghana P.O. Box TL 1140 Tamale

ETHICAL APPROVAL - ID NO: GHS-ERC: 09/09/13

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol titled:

"Contribution of mental health service and policy in Ghana-The case of mental health society of Ghana"

This approval requires that you inform the Ethical Review Committee (ERC) when the study begins and provide Mid-term reports of the study to the Ethical Review Committee (ERC) for continuous review. The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Please note that any modification without ERC approval is rendered invalid.

You are also required to report all serious adverse events related to this study to the ERC within seven days verbally and fourteen days in writing.

You are requested to submit a final report on the study to assure the ERC that the project was implemented as per approved protocol. You are also to inform the ERC and your sponsor before any publication of the research findings.

Please always quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED......DR. CYNTHIA BANNERMAN

(GHS-ERC VICE-CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

Faculdade de Ciências Médicas Comissão de Ética (Presidente: Prof. Doutor Diogo Pals)

TO WHOM IT MAY CONCERN

The Ethics Committee of the Faculty of Medical Sciences of the New University of Lisbon (Faculdade de Ciências Médicas da Universidade Nova de Lisboa, FCM-UNL - CEFCM) has unanimously approved the Research Project entitled 'Contribution of mental health service user groups to mental health services and policy in Ghana – The case of Mental Health Society of Ghana (MEHSOG)' (nr. 19/2013/CEFCM), submitted by Dr. Badimak Peter, Yaro.

Lisbon, December 16th, 2013

The Chairman of the Ethics Committee,

(Diogo Pais, MD, PhD)

Campo dos Mártires da Pátria, 130 1169-056 Lisboa Portugal Tel. 21 8803039
Email:cefcm@fcm.uni.pt